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**Experiences of Staff Working in Services for Adults with Intellectual
Disabilities**

Elinor Pegg

Doctorate in Clinical Psychology

University of Edinburgh

August 2013

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Content and format

This portfolio contains three chapters; a systematic review, a journal article and an extended methods chapter. The focus of the thesis was the experiences of paid staff working with adults with Intellectual Disabilities (ID). The research project aimed to gain an understanding of the experiences of support staff working with clinical psychologists in the development of support guidelines for challenging behaviour. It was not possible to conduct a review of the literature regarding the topic of the research project due to the lack of previous research in this area. Therefore, the systematic review provides a summary of the current evidence regarding interventions aimed at reducing stress in staff that support adults with ID. The review topic was chosen due to its relevance to the research topic and significant clinical implications.

The systematic review adheres to the author guidelines issued by the Journal of Applied Research in Intellectual Disability and the journal article to the guidelines for Research in Developmental Disability. The method chapter conforms to the guidelines issued within the University of Edinburgh Doctorate in Clinical Psychology Handbook.

The term Intellectual Disability was used throughout the portfolio as this is the term used in the selected journals, although the author is aware that the term Learning Disability is commonly used in the UK and NHS services.

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Thesis abstract

Background: As a result of the changes in support for adults with Intellectual Disabilities (ID) and the increasing emphasis on independent living within the community, individuals commonly live in their own homes with support provided by voluntary or private services. As a result, support staff play a huge role in the lives of adults with ID and are often the mediators of interventions aimed at reducing distress or the occurrence of challenging behaviour. Issues relating to the well-being of support staff and how they manage behaviours that challenge services are central to the quality of the lives of adults with ID.

Method: A systematic review was carried out regarding interventions aimed at reducing stress felt by staff supporting adults with ID, with the aim of informing the clinical practice of psychologists that work with such staff groups. An empirical study employing the qualitative methodology of grounded theory was also conducted to explore the experiences of staff working with clinical psychologists outside of their organisation in the development of support guidelines aimed at reducing challenging behaviour.

Results: Findings from the Systematic Review highlighted the lack of high quality intervention studies aimed at reducing stress in staff. Some tentative support was found for interventions based on Acceptance and Commitment Therapy and those taking a more practical problem-solving approach. The empirical study resulted in a tentative model within which the role of expectations was highlighted as key to staff's experiences of working with professionals.

Conclusion: Further research is required in order to identify the most effective ways to reduce stress experienced by staff working with adults with ID. The constructed theoretical model suggests ways in which psychologists can understand the experience of staff and has implications for their practice.

Chapter 1: Systematic Review

Stress Reduction Interventions for Staff Working in Intellectual Disability Services: A Systematic Review

Abstract:

Aim: This paper reviews the evidence regarding interventions aimed at reducing stress in paid staff working with adults with Intellectual Disability (ID).

Method: A systematic search of the peer-reviewed published literature was conducted using five electronic databases. The quality of papers was evaluated in relation to predetermined criteria.

Results: Twelve papers were reviewed, however the findings of three were excluded due to poor quality. A variety of approaches were taken to intervention, however few had an explicit theoretical basis. All papers reported some positive changes post intervention, commonly of small effect size. One paper reported negative changes post intervention.

Conclusions: There is some evidence of the efficacy of stress reduction interventions in this population, however further research using more robust methods is required to determine the most effective styles of intervention.

Keywords: Intellectual Disability, staff, stress, stress reduction.

Introduction

As Cox (1978) noted over 30 years ago, 'the concept of stress is elusive' (p.1) and even today is still viewed as complex and difficult to define. This is partly due to the term being defined as the perception of stressors, the immediate experience and the consequences in emotional, behavioural and cognitive terms (Ayers and Steptoe, 2007). One commonly used definition is that stress is 'a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources' (Lazarus and Folkman, 1984, p. 19). Other accounts, however, place more emphasis on its effects, defining stress as the failure of normal functioning with symptoms related to anxiety and depression as common first signs (McManus, 2007, p. 501).

Stress can also be described in terms of the context it occurs in, for example, work related or occupational stress. Long term occupational stress can lead to severe distress and burnout (Weinberg and Creed, 2000), particularly among staff in human service roles (Borritz et al., 2010). Burnout has been defined in many ways, however definitions commonly centre around physical, emotional and mental exhaustion (similar to general distress, Cordes and Dougherty, 1993), along with reduced feelings of accomplishment and motivation, dysfunctional and depersonalising attitudes towards service users (Skirrow and Hatton, 2007). Burnout is commonly viewed as a specific form of psychological stress (Firth-Cozens and Payne, 1999). For the purposes of the following review, all the above definitions of stress and its effects will be considered when making reference to 'stress'.

Occupational stress has been shown to have various effects in the wider health sector, including increased depression and physical symptoms in staff working in long term nursing provision (Schaefer and Moos, 1996) and sickness absence in those working in various health sector jobs; in one study an increase of 1 standard deviation on a work related burnout scale predicted a 21% increase in days absence per year (Borritz et al., 2006).

Stress in support staff

Staff are one of the most important components of the system that surround those with ID living in supported residential settings and constitute one of the biggest areas of expenditure for services (Rose, 2011). In addition to the usual work stressors this staff group face the additional impact of exposure to challenging behaviours such as self-injurious behaviour, verbal and physical aggression. Research indicates that they experience significant levels of stress (e.g. Robertson et al., 2005); despite a pattern of gradually decreasing levels over the past 20 years (Skirrow and Hatton, 2007).

The impact of occupational stress on the individual is an important issue in its own right; employers have been suggested to have a moral and legal responsibility for staff welfare (Hastings, 2002). Occupational stress in staff who support adults with intellectual disabilities (ID) has been widely researched and various associations have been reported, for example with increased symptoms of depression (Gray-Stanley et al., 2010). Stress can also impact on the care provided by staff by contributing to high rates of staff turnover (Jenkins et al., 1997) and absenteeism (Razza, 1993). Both of these are likely to affect consistency in the delivery of support, a key factor for high quality support (Royal College of Psychiatrists et al., 2007).

Stress has also been suggested to affect staff reactions to challenging behaviour (Hastings, 2002, Rose et al., 2004), and therefore has implications for the implementation of support guidelines. Staff with lower stress levels (Rose et al., 1998a, as measured by the Thoughts and Feelings Index (Fletcher, 1989)) and lower levels of emotional exhaustion (Lawson and O'Brien, 1994) have been found to provide more positive interactions with the individuals they support. By contrast, there is a suggested increase in risk of abusive practices occurring in organisations with high staff stress and burnout (White et al., 2003). Therefore, staff stress is relevant both to the immediate quality of life of the individuals with ID and potentially in the longer term development of challenging behaviour (Hall et al., 2001).

It should, however, be noted that despite a number of studies indicating a negative impact of stress on staff behaviour and the support provided, in many cases these proposed relationships have not been proven empirically (e.g. Hastings, 2002), are based on single correlation studies (e.g. Thomas and Rose, 2010) or have often found only weak relationships (e.g. Lawson and O'Brien, 1994). Therefore there is still a need for further research to clarify the effects of stress in this population (Hatton et al., 2008).

Given the complex conceptual nature of stress, it is unsurprising that research has taken a number of approaches. Studies have focused on assessing the various factors associated with stress including organisational factors (e.g. Thompson and Rose, 2011), perceived social support and role ambiguity (Dyer and Quine, 1998), disengaged/avoidant coping styles, in particular wishful thinking (Devereux et al., 2009b, Hastings and Brown, 2002), self-efficacy (Howard et al., 2009), work overload and limited decision making (Gray-Stanley and Muramatsu, 2011). There has also been interest in the specific effects of challenging behaviour on staff psychological well-being, with a suggested mediating role of negative emotional reactions (Hastings, 2002). These studies indicate a number of factors may be indicated in staff stress, however as noted by Hatton and colleagues (2004), there is a need for studies measuring a range of factors and using multivariate analyses.

A variety of theoretical approaches have also been adopted include person - environment fit, demands- constraints theory, cognitive-behavioural, emotional overload, and equity theory. Space precludes a full description of these theories (see Devereux et al., 2009a for further discussion), however, this list illustrates that a number of theoretical approaches are available to researchers in this field.

Stress reduction interventions

The previously discussed literature suggests that there are a number of potential benefits to reducing staff stress. The conceptual complexity of stress and large number of contributing factors indicates a range of potential areas for intervention (Rose, 1997). Such interventions can be categorised according to their theoretical

background; such as equity theory (e.g. van Dierendonck et al., 1998) or Acceptance and Commitment Therapy (ACT) (e.g. Bethay et al., 2013); the timing i.e. if they are preventative or aimed at treating symptoms; or by the target of the intervention e.g. to reduce/ remove the stressors or reduce the impact of the stressor (Innstrand et al., 2002). They can also be separated according to the locus of the intervention e.g. distinguishing person-directed from organisation-directed interventions (Marine et al., 2006). Interventions focusing on the individual can take a number of forms: changing the goals and expectations of the staff, changing the appraisal of the stressors or increasing psychological resources e.g. coping substitutes to the withdrawal seen in burnt out individuals (Cherniss, 1980).

A number of recommendations have been made in relation to stress interventions. Cherniss (1980) suggests that interventions should be based on 'empirical analyses and the most plausible theory' (pg.158). He recommends that they should take a preventative stance and should focus on the work setting, as it is easier to intervene there than at an individual characteristic or societal level. Some suggested strategies include: changing job roles, management development, organisational problem-solving and decision-making, altering agency goals and philosophies. He cautions against defining solutions in terms of additional resources as this alone is not sufficient for change, and highlights the importance of awareness within management. Rose and colleagues (2005) suggest a number of additional factors that contribute to effective intervention packages: interventions should be repeated regularly, be embedded within a problem solving approach and occur within the context of more general stress reduction efforts, including projects aimed at organizational change.

With these guidelines in mind, the aim of this review is to evaluate the evidence regarding the effectiveness of interventions to reduce stress in workers who provide support to adults with intellectual disabilities.

Method

Search strategy

Searches were conducted in January 2013 and publication year was unrestricted. The following electronic databases were used to identify published research: Medline (1946-2012), PsycINFO (1987-2012), Embase (1980-2012), Cinahl (1990-2012) ERIC (1966-2012) and ASSIA (1989-2012). Existing systematic reviews in similar areas were used to identify appropriate keywords in addition to using the MeSH dictionary. Search strings specific to each database were devised combining terms for intellectual disability, staff and stress (see appendix 1). Terms were searched for as MeSH terms when indicated and in the domains of title, abstract and keywords in all other instances.

Titles of all search results were scanned for relevance and the abstracts of potential papers were reviewed. The full text was gained for papers deemed potentially relevant. Citation searches were conducted using Web of Knowledge, the reference lists of the included articles were hand searched, as were the journals of Work and Stress and the International Journal of Stress Interventions (chosen due to their relevance to the field).

Inclusion criteria

Studies were included if: they were published in an English language journal and subjected to a peer review process; evaluated an intervention aimed at preventing or reducing stress (as previously defined in the introduction) experienced in the work environment of paid staff who supported adults with intellectual disabilities (studies including mixed staff groups were included); took place in non-clinical environments i.e. excluding acute medical settings; and included a tool stated to measure stress (as previously defined in introduction, therefore including the perception of stressors, subsequent emotional reactions and burnout). If a measure of stress was included, secondary outcomes of the detrimental effects of stress were also considered. Secondary outcomes included psychological symptoms such as depression or anxiety. No restrictions were placed on the type of intervention delivered based on format, theoretical underpinnings or methodology. In the case of papers supplying insufficient information to be certain regarding inclusion criteria, the studies were included.

Data collection and assessment of quality

Each included study was summarised on a purpose made data extraction form detailing the following information: study design and measures, participants (number, age, gender, context of working environment), sampling, intervention description, data reported, analysis and findings.

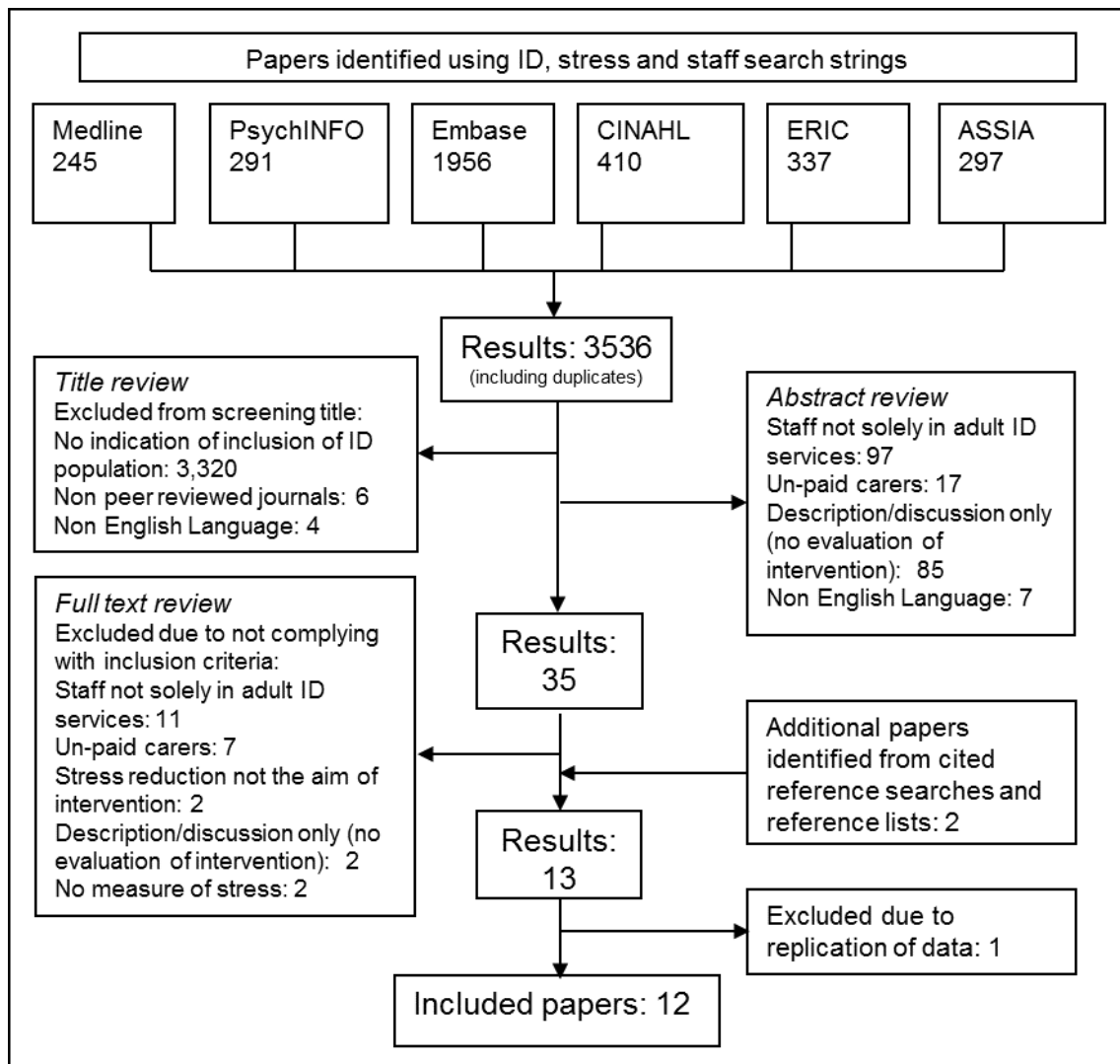
The assessment of methodological quality of the included studies was carried out using a quality assessment tool (see Appendix 2) adapted from published quality criteria i.e. the Scottish Intercollegiate Network Guidance (Scottish Intercollegiate Guidelines Network, 2001) and the Consolidated Standard for Reporting Trials (Schulz et al., 2010), Deeks and colleagues (2003), and Downs and Black (1998). Sixteen aspects of each study were assessed covering criteria including risk of bias, choice of measure, statistical analysis, intervention quality and quality of reporting, as recommended by the Centre for Reviews and Dissemination (CRD) at the University of York (www.york.ac.uk/inst/crd/). Each criterion was rated on a scale of 0 (not addressed/not reported) to 3 (well covered). An independent person carried out extraction and quality assessment for 4 papers (33%). Exact agreement occurred on 92% of scores. There was a difference of one point on the remainder of scores. Scoring discrepancies were discussed and a joint decision was reached.

Data synthesis was not carried out due to the lack of sufficient detail reported in the majority of studies and variety of interventions employed. Interventions and statistically significant findings are reported and discussed in a narrative fashion.

Results

The electronic database searches produced 3535 results. Two further papers were identified from citation searching or reference lists of relevant papers. Figure 1 displays the search process.

Figure 1. Flow diagram of literature search process



Characteristics of included papers

Table 1 below summarises the study characteristics and findings of the included papers. Means and standard deviations are included where available. Studies were numbered chronologically and will be referred to as S1-S12 for the remainder of the results section.

Interventions took a range of approaches; three used ACT (S1,S3,S4), one mindfulness (S2), one described as employing cognitive-behavioural techniques (e.g. cognitive restructuring and relaxation, S8), four problem-solving type interventions (S6,S7,S9,S10), one applied managerial strategies (S11) and one

provided stress inoculation training (S12). All but one (S11) intervention included aspects aimed at reducing the impact of stressors on individuals. Five aimed to reduce/remove stressors (S6,S7,S9,S10,S11). Five interventions were at the level of the individual only (S1,S2,S3,S4,S12) and six involved both individual and organisation-directed aspects (S4,S5,S6,S7,S8,S9). All interventions used a group format and total intervention length varied from three hours (S9) to two and a half days (S7). It was not possible to identify the length of the interventions in study 4 or 11. None of the studies explicitly stated if the intervention had a preventative or curative aim, however, it could be assumed that in the absence of inclusion criteria regarding pre-intervention distress levels, studies were taking a preventative approach. Studies took place in a variety of countries and participant job roles varied, with four studies (S1,S2,S3,S4) including a proportion of staff with managerial responsibilities or other roles such as teachers and psychological technicians (S1).

Table 1. Summary of study characteristics and findings

| Study, Country | Participants, Setting and Selection | Study design and Measures | Intervention | Analysis and Findings (statistically significant findings only) |
|--------------------------------|--|--|---|---|
| S1.(Bethay et al., 2012), USA. | Participants: n= 34 (38 consented). Psychologists and psychological technicians: (n=14), special education and assistant teachers (n=11), direct care staff (n=10), nurses (n=2), and social workers (n=1). 76.5% female, mean age 38yrs (range= 22–60), mean employment length 7.6yrs (range = 0.17–26). Setting: Large residential facility. Selection: Not described. Random assignment to groups. | Design: Pre-post (immediate, 3 mths). Intervention (n =20) with control (n=18). Measures: GHQ- 12 (Goldberg, 1978), Maslach Burnout Inventory, Human Services Survey (Maslach et al., 1996), Burnout Believability Scale (developed by authors). | 3 3hr group sessions administered at 1wk intervals. Intervention: 6hrs of Acceptance and Commitment Training developed by authors (based on three previous protocols (Hayes et al., 2004, Bond and Heyes, 2002, Blackledge and Hayes, 2006) with practice exercises for homework, plus 3hs of training in the principles of applied behaviour analysis. Control: 9hrs of didactic training in principles of Applied Behaviour Analysis. | Analysis: Repeated-measures ANOVAs (Intervention n=18, control n=16) and between group t-tests for outcomes. Mann–Whitney U to compare those with higher or lower pre-test GHQ scores. Findings: Participants who reported not to have practiced techniques (n=6) exhibited lower pre-test GHQ scores, emotional exhaustion and depersonalization scores than practicers (n=28). Intervention group participants who reported having practiced (n=14) showed a greater reduction in GHQ-12 scores than control (n=14) at post-intervention but not at 3mths. Those scoring at or above clinical cut off for psychiatric distress on GHQ at pre-test, the intervention group (n=5) had a greater decrease in GHQ scores than control (n=9) at post-test and follow up. |

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| <p>S2.(Brooker et al.2012). Australia.</p> | <p>Participants: n=29 (34 consented, 80% of population), 59% female. Managers n=22, mean age 46.5yrs. Support workers n=12, mean age 36yrs. Setting: Two community homes. Selection: Participation voluntary, all staff invited.</p> | <p>Design: Single group pre-post (immediate) Measures: Five Facet Mindfulness Questionnaire (FFMQ, Baer et al., 2006), Patient Health Questionnaire (PHQ-9 Kroenke et al., 2001), Perceived Stress Scale (PSS, Cohen et al.,1983), Depression Anxiety Stress Scale (DASS-21, Lovibond and Lovibond, 1995), Positive and Negative Affect Schedule (PANAS, Watson et al., 1988), Copenhagen Burnout Inventory (CBI, Kristensen et al., 2005), Satisfaction with Life Scale (Diener et al., 1985), Minnesota Satisfaction Questionnaire Short Form (Weiss et al., 1967), Professional Quality of Life Scale (Stamm, 2009). Santa Clara Brief Compassion Scale (Hwang et al., 2008), Self-compassion Scale (Neff, 2003).</p> | <p>8 weekly 2hr sessions. 'Occupational Mindfulness' group-based training program, adapted from a Mindfulness Based Cognitive Therapy (MBCT) manualised training program for depression relapse prevention (Segal et al., 2002). Largely experiential, covering techniques including mindfulness of breathing, body scan meditation and mindful stretching, sitting and walking. Home practice expected of 40min daily, 6 days a week.</p> | <p>Analysis: Wilcoxon signed-rank test to calculate changes in mindfulness and psychological wellbeing from pre (n=34) to post n=29 (85%). Findings: Increase in positive affect (ES=0.33, small) post training with increases in negative affect (ES= 0.42, medium), anxiety (ES=0.75, medium), DASS-21 stress (ES=0.35, medium) and total score (ES=0.51, medium), Perceived Stress Scale (ES=0.28, small).</p> |
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| <p>S3. (Smith and Gore, 2012). U.K.</p> | <p>Participants: n=14, (72 consented). 66% female, aged 18-67. Registered nurses: n=36 (including 9 managers). Non-registered nurses: n=25. Behaviour Specialists/Assistant Behaviour Specialists: n=11, 1- 40 years' experience (modal group= 21-30years). Setting: 'Challenging behaviour services', Selection: Not described.</p> | <p>Design: 6 groups (assignment by convenience) started at monthly intervals, pre-post (1mth pre group, start of group, immediately post, 3mths and 6mths). Measures: The General Health Questionnaire – 12 (Goldberg, 1978), Dysfunctional Attitude Scale (Weissman and Beck, 1978), Maslach Burnout Inventory (Maslach et al., 1996), Staff Stressor Questionnaire (Hatton et al., 1999), Acceptance and Action Questionnaire (Heyes et al., 2004), Support Staff Values Questionnaire (Noone and Hastings, 2011).</p> | <p>1 day workshop and half day follow --up 'several weeks' later (6 groups, maximum 12 people each) using ACT intervention (based on (Noone and Hastings, 2009). Introducing 5 core ACT principles: Stress is normal, how we use language and thoughts to problem solve, the down side to living in our thoughts, alternatives to living in our thoughts and being led by our values, not our thoughts.</p> | <p>Analysis: Friedsman's Test followed by Wilcoxon Signed Ranks Tests for each time point (1mth prior n= 62 (86%), pre n=66 (92%), post n=49 (68%), 3mths n=20 (28%), 6mths n= 14 (19%)). Findings: Decreased depersonalisation scores between post intervention and 3mth follow up (ES r=0.52, large) and between 1mth prior to group and 3mth follow up (ES r=0.38, medium). Reduction in GHQ-12 score between 1 month prior to group and post intervention (ES r=0.45, medium), and pre interventions and 3mth follow up (ES r=0.44, medium). Perception of stressors reduced between 1mth prior and 3mth follow up (ES =0.36, medium) and post intervention and 3mth follow up (ES r=0.54, large), and between post intervention and 6mth follow up (ES r=0.51, large). Decrease in indicators of dysfunctional attitudes between post intervention and 3mth follow up (ES r=0.44, medium).</p> |
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| S4. (Noone and Hastings, 2010). U.K. | <p>Participants: n=34 direct support staff (64 consented). Including 6 with nursing or social work qualifications (4 managers). 71% female, mean age 41.71yrs (range 23-58, SD=10.11). (n=14 from Noone and Hastings, 2009).</p> <p>Setting: Community homes (NHS and independent) organisations.</p> <p>Selection: Not described.</p> | <p>Design: Single group pre-post (follow-up session).</p> <p>Measures: General Health Questionnaire-12 (Goldberg, 1978), Staff Stressor Questionnaire (Hatton et al., 1999).</p> | <p>1 day workshop and half day follow up 'several weeks' later (number of groups and sizes not reported), using Promotion of Acceptance in Carers and Teachers (PACT), and Acceptance and Commitment Therapy based package (based on Bond and Bunce, 2000). Assignment to group according to convenience and availability based on locality.</p> | <p>Analysis: All data pooled. Related samples t-test and Mann-Whitney (n=34)</p> <p>Findings: Reduced GHQ total score post intervention (ES =0.48, medium). Staff who had no professional level qualifications, had increased GHQ-12 scores pre-intervention, and who reported more work related stress on the SSQ pre- intervention had larger reductions in GHQ scores from pre to post PACT.</p> |
| S5. (Long et al., 2008). UK. | <p>Participants: 12 staff.</p> <p>Setting: 12 bedded medium secure ward for women with development disabilities. Selection: not described.</p> | <p>Design: Single group pre-post (immediately pre interventions, 6mths).</p> <p>Measures: Work Environment Scale (Moos, 1986), Maslach Burnout Inventory (Maslach, 1982), Job Description Index (Smith et al., 1969), Disturbed Behaviour List (Trauer, 1983).</p> | <p>Programme of staff education including behavioural analyses and RAID (Reinforce Appropriate, Implode Disruptive, Davis, 2001). Interventions aimed at changing attitudes (e.g. 'treatment programme development meetings'). Increasing support by reflective practice groups and increased feedback of patient outcome measures to staff. Therapy programmes for patients. Increased service user involvement.</p> | <p>Analysis: Wilcoxon Signed Ranks Tests.</p> <p>Results: Relationship dimension of WES: increase in Involvement and Cohesion. Personal Growth dimension: increased Autonomy and Task Orientation. System maintenance and Change dimension: increased Clarity. Decreased Emotional Exhaustion and Depersonalisation and increased Personal Accomplishment. Decreased Total Behavioural Disturbance.</p> |

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| S6. (Hodgkins et al., 2005). UK. | Participants: n=36 support staff (46 consented, 56% of population). 88% female. Setting: Four community homes supporting 36 clients. Selection: Not described. | Design: Single group, Pre-post (3mths). Measures: Demands and support Questionnaire (Rose, 1999), Staff Support Questionnaire (Harris and Rose, 2002), Team Climate Inventory (Anderson and West, 1999), Maslach Burnout Inventory (Maslach et al., 1996), Anxiety (Fletcher, 1989). | 1 day workshop facilitated by authors followed by review meeting 3mths later. Results of initial questionnaires used to create a report discussed at 1 st workshop introducing stress models, stress management and problem solving. Goals were set within each staff group according to needs identified in workshop. Review meeting at 3mths. Further meeting to discuss goals and future meetings arranged. | Analysis: Independent samples t-tests conducted on pre (n= 46) and post (n=36) scores. Findings: Anxiety and emotional exhaustion (MBI) scores were lower post intervention, as were perceived demands resulting from resident interaction and work pressure. |
| S7. (Innstrand et al., 2004). Norway. | Participants: n= 47 (65 consented, 62% of population) direct care staff. Whole sample: 90% female, mean age 40yrs (range= 21-65yrs). Setting: Community homes in two areas. Selection: Questionnaire sent to all staff, voluntary participation. | Design: Pre-post (10mths apart). Control group in another locality. Measures: Measure of sources of stress developed by authors, General Burnout Questionnaire, (later named Maslach Burnout Inventory - General Survey, Schaufeli et al., 1995), (adapted by Mykletun, 1999), job satisfaction scale. | Intervention: 2 workshop days 10mths apart. Questionnaire designed by author regarding: stressors and burnout. Results discussed at 1 st workshop. Participants divided into 4 groups to devise resolutions for stressors identified in questionnaire. Strategies agreed in workshop at personal and organisational level e.g. exercise programme, educational seminars, working schedule review. 2nd workshop to discuss progress and further goals. Control: no intervention. | Analysis: ANCOVA comparing intervention (pre n=43, post = 36, both n=22) and control (pre n=22, post n= 11, both n=9) groups with pre intervention values as covariates. Findings: Intervention groups showed reduction in perceived sources of stress and exhaustion and increase in job satisfaction. |

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| S8. (van Dierendonck et al., 1998). The Netherlands. | <p>Participants: 149 direct care workers (352 consented). Of final sample: 72% female, mean age 33.4yrs (SD=6.7), mean work experience 7.2yrs (SD = 5.7).</p> <p>Setting: Few details provided. Selection: Participants identified by managers.</p> | <p>Design: Pre-post (6mths, 1yr). Intervention (n = 84), with 2 control groups (n=80 from within organisation, n=190 out with the organisation). Measures: Absenteeism and turnover (measured for 1yr). Maslach Burnout Inventory (Maslach and Jackson, 1986), equity (designed by authors), perceived social support (designed by authors).</p> | <p>Intervention: 5 half-day group (6-8 participants) program run weekly by Psychologist. Based on equity theory with a cognitive-behavioural orientation. Aimed at reducing perceptions of inequity in the relationship with the organization and service users. Methods included cognitive restructuring, relaxation and psycho-education regarding burnout. 3 workshops for management on communication and social skills. Control: no intervention.</p> | <p>Analysis: ANOVAs to detect differences between experimental (n=36) and 2 control groups (n=39 from within organisation and n=74 out with) at three time points. MANOVAs to determine selection effect. Findings: Experimental group emotional exhaustion was less than controls at 6 and remained stable until 12 months (ES partial $\eta^2= 0.26$). Personal accomplishment decreased at 6months but returned to baseline levels by 12months. Absence duration decreased in experimental group whereas it increased in internal controls. Deprived feelings with respect to organisation were less in the experimental group than controls at 6 and 12 months, particularly in those with higher perceived social support.</p> |
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| S9. (Rose et al., 1998b). U.K. | <p>Participants: n= 28 direct care staff (38 consented). Intervention: 73% female. Control: 77% female. Setting: 5 community homes. Selection: Houses selected by management as having perceived issues of staff well-being. Random assignment of participants to groups.</p> | <p>Design: Pre-post (2-6wks following final workshop). Intervention (n=15) with 3 control groups (n=23). Measures: Part 1 of the Adaptive Behaviour Scale (Nihara et al., 1974), Behaviour Problems Inventory (Rojahan et al., 1989), Demands and Support Questionnaire (Rose, 1993), Thoughts and Feelings Index (Fletcher, 1989). Intervention group observations of over 24 occasions totalling 36hrs.</p> | <p>2 1 day workshops 4-5 months apart with intervening 1hr meeting. Report based on Demands and Support Questionnaire (Rose, 1993) responses used to discuss organisational and personal sources of stress and potential resolutions using problemsolving format. Review of progress 8-10wks and 16-20wks post intervention. Final session included presentations to develop team functioning (Lewis 1991). Control: no intervention. Report fed back after completion of study.</p> | <p>Analysis: MANOVA used to assess withinsubjects change for intervention (pre n= 14) post n= 13 and control (pre n= 18, post n= 15) groups. Independent t-tests to compare observation data. Findings: Anxiety reduced post intervention in intervention group but not control (ES $\eta^2= 0.11$, small, but non-significant interaction). Perceived support increased over time in the intervention group but not in the control group (ES $\eta^2= 0.13$, small). Increases in staff positive interaction, assistance, formal education and social interaction with peers post intervention.</p> |
| S10. (Gardner and Rose, 1994). U.K. | <p>Participants: 18 support staff. Setting: Day centre. 100 Service users, 24 staff. Selection: Authors approached by Day Centre managers. Voluntary participation.</p> | <p>Design: Single Group pre-post (1wk and 8mths). Measures: Thoughts and Feelings Index (Fletcher, 1989).</p> | <p>3 1hr sessions over 5wks. Questionnaire designed by authors covering perceptions of stress, sources of stress, ways of coping and measure of strain (effects of stress). Discussion at workshop regarding areas of questionnaire. Presented model of organisational stress and goals set to reduce specific work stressors. Goals included managerial decisions (e.g. upper limit on service user numbers), organisational issues (e.g. quiet place for breaks, study days and</p> | <p>Analysis: not reported. Results: no significant changes reported.</p> |

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| | | | further 1.5 days stress and change workshop. | |
| S11. (Swanson, 1987). USA. | Participants: 9 support staff. Setting: 3 community homes. Selection: Not described. | Design: Pre-post, (immediately post each intervention phase, 4wks follow-up). Measures: Stress evaluation scale (designed by author). | Managerial strategies (monitoring and feedback to staff and managers on client educational interventions), goal setting (values priority scale with staff and administrators used to clarify current goals), job enrichment (employee inventory to identify strengths and deficiencies of systems to identify areas for change) implemented in turn for 4wks each. | Analysis: Friedman two way analysis of variance by ranks test (2 tailed). Results: Reduction in stress post intervention but not at follow-up. When analysed separately, 1 of 3 houses (N=3) had significant reductions. |

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| S12. (Keyes and Dean, 1988). USA. | Participants: 100 direct care staff. Intervention group: 72% female, mean age 30.88yrs, mean experience 4.9 yrs. Control: 70% female, mean age 30.8yrs, mean experience 5.3yrs. Setting: 3 'Intermediate Care Facilities', supporting 32, 150 and 85 people. Selection: Random selection. Allocation to groups by convenience. | Design: Pre-post (immediate). Intervention (n=50) with control (n=50) from 2 other facilities. Measures: Anger Inventory (Novaco, 1975), training evaluation questionnaire (repeated 3.5 months post intervention). Frequency of emergency restraint monitored for 5 months pre and post intervention in facility 1. | 1 day workshop (12-16 people) of Stress Inoculation Training based on Meichenbaum's (1985) programme. Covering: conceptualisation (cognitive model of stress presented), skill acquisition rehearsal (coping skills including problem solving and relaxation) and 'application and follow through' (practice of techniques using role play). Control: groups lasting 12hrs (3-4 participants) given cognitive behavioural based lecture and discussion on stress and anger. | Analysis: ANOVA for intervention (pre n= 50, post n=50) and control pre (pre n= 50, post n= 50) groups. Chi square one sample test on restraint data for intervention group only. Findings: Reduction in Anger Inventory scores in intervention compared to control group. Male's scores reduced more than females in intervention group. Reduction in emergency restraint following intervention. |
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ES= effect size, Cohen's d unless otherwise stated.

The main outcome measures included a variety of constructs using a range of tools. Stress was described as being measured by: Perceived Stress Scale (Cohen et al., 1983, S2), Demands and Support Questionnaire (Rose, 1999, S6,S9), Staff Stressor Questionnaire (Hatton et al., 1999, S5,S6), Thoughts and Feelings Index (Fletcher, 1989, S9,S10) or a scale developed by the authors (S7,S11). Three studies (S1,S3,S4) used a measure of psychological distress (General Health Questionnaire, GHQ-12, Goldberg, 1978). Study 12 used the Anger Inventory (Novaco, 1975) as a measure of 'a maladaptive stress reaction' (p. 317).

Burnout was measured using three tools, commonly the Maslach Burnout Inventory, Human Services Survey (Maslach et al., 1996, S1,S3,S6) or similar versions (S4,S7,S8). Aspects of affect were also measured including anxiety and depression e.g. the Depression Anxiety Stress Scale (DASS-21, Lovibond and Lovibond, 1995, S2). Other outcomes included turnover intention (S8), absenteeism (S8), frequency of emergency restraint (S12), feelings of equity (S8) and staff support (Staff Support Questionnaire, Harris and Rose, 2002, S6). Four studies included measures of process (S1,S2,S3,S8), two of which were developed by the authors (S1,S8).

Quality assessment

Table 2 displays the scores for included studies according to each of the quality criteria, providing an indication of the relative methodological strengths. Quality of studies was low; the average score was 18 out of a possible 48 (range 5-31) with 10 studies scoring less than 50% of the possible total.

The level of detail provided regarding participants and settings varied. Only two studies received a rating of 'well covered' (S1,S2) and only one stated inclusion and exclusion criteria (S2). None of the studies included a sample size determined by a power calculation and post intervention group sizes varied from 9 (S11) to 50 (S12). Of the six studies that included a control group (S1,S7,S8,S9,S12), only two were an intervention control (S1,S12). Only two studies described allocation to groups as random (S1,S9, however, neither described the method of randomisation) and in

two studies control group equivalency was either not assessed (S12) or differences were found that were not accounted for in the analysis (S7). Measurement of intervention fidelity was the second lowest scoring criteria, however given the idiosyncratic nature of a number of the interventions (S5,S6,S7,S8,S9,S10), fidelity measurement was not always possible. Adherence was not commonly recorded and attendance at sessions was not clearly described by most, and when reported it was often quite low (e.g. 33% attended the final session of S10, 56% attendance at S4 follow up session). Length of follow-up was generally short; only three studies included follow-up periods greater than 3 months post intervention: 6 (S3), 8 (S10) and 12 months (S8). Measures were generally judged as appropriate for the aims of the study, however the sole use of the Thoughts and Feeling Index (Fletcher, 1989), which is comprised of anxiety and depression subscales, could be argued to be a limited measure of stress. Analysis was considered poorly addressed by one study which used independent t-tests to compare pre and post intervention data (S6). Attrition rates of many studies were high; study 10 received only a 19% response rate at 6 months. Only two studies (S4,S8) made comparisons to determine potential differences between those who dropped out and those who remained within the study. Results were generally adequately documented however only five studies reported effect sizes (S2,S3,S4,S8,S9).

Studies scoring 0 on 7 or more criteria (S5,S9,S11) were excluded from further discussion due to their poor quality.

Table 2. Quality criteria scores.

| Study | Quality criteria | | | | | | | | | | | | | | | | |
|--------------------------------|----------------------|----------------------------|----------------------|-------------------------|------------------|-------------------------------------|----------------|-------------------|-------------------------------------|----------------------|------------------------------|------------------------------|-------------------------------|--------------|-------------------------|----------------------|---|
| | 1. Statement of aims | 2. Participant description | 3. Sampling strategy | 4. Use of control group | 5. Randomisation | 6. Blinding of allocation to groups | 7. Sample size | 8. Measure choice | 9. Measure validity and reliability | 10. Follow up length | 11. Intervention description | 12. Fidelity to intervention | 13. Adherence to intervention | 14. Analysis | 15. Attrition addressed | 16. Results reported | Total out of 48/ rank (number of criteria ranked 0) |
| 1. Bethay <i>et al</i> , 2012 | 3 | 3 | 1 | 3 | 1 | 0 | 0 | 3 | 2 | 2 | 3 | 0 | 1 | 3 | 3 | 2 | 30/2nd (3) |
| 2. Brooker <i>et al</i> , 2012 | 3 | 3 | 2 | 0 | 0 | 0 | 0 | 3 | 3 | 1 | 1 | 3 | 3 | 3 | 3 | 3 | 31/1 st (4) |
| 3. Smith & Gore, 2012 | 2 | 2 | 0 | 1 | 0 | 0 | 0 | 3 | 1 | 2 | 3 | 0 | 0 | 3 | 1 | 2 | 20/5 th (6) |
| 4. Noone & Hastings, 2010 | 1 | 2 | 0 | 0 | 0 | 0 | 0 | 2 | 1 | 1 | 3 | 0 | 1 | 3 | 2 | 2 | 18/7 th (6) |

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|--------------------------------|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|-------------------------|
| 5. Long et al, 2008 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 1 | 1 | 0 | 0 | 2 | 0 | 1 | 7/=10th(10) |
| 6. Hogkins et al, 2005 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 2 | 1 | 2 | 1 | 0 | 0 | 0 | 1 | 2 | 11/9 th (8) |
| 7. Innstrand et al, 2004 | 2 | 1 | 1 | 1 | 0 | 0 | 0 | 3 | 2 | 1 | 1 | 0 | 0 | 3 | 1 | 1 | 17/8 th (5) |
| 8. Van Dierendonck, et al 1998 | 3 | 1 | 1 | 1 | 0 | 0 | 0 | 3 | 1 | 3 | 2 | 0 | 0 | 3 | 2 | 3 | 23/3rd(5) |
| 9. Rose et al, 1998 | 3 | 1 | 0 | 1 | 1 | 0 | 0 | 2 | 1 | 1 | 2 | 0 | 0 | 3 | 1 | 3 | 19/6 th (5) |
| 10. Gardner & Rose, 1994 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 3 | 1 | 0 | 1 | 0 | 0 | 1 | 5/11 th (10) |
| 11. Swanson, 1987 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 1 | 0 | 0 | 1 | 1 | 1 | 7/=10 th (9) |
| 12. Keys & Dean, 1988 | 2 | 2 | 2 | 3 | 0 | 0 | 0 | 2 | 1 | 1 | 1 | 0 | 0 | 3 | 3 | 2 | 22/4th (5) |

Scores: 3 = well covered. 2 = adequately addressed. 1 = poorly addressed. 0 = not reported/not addressed.

Summary of main study findings

ACT and mindfulness based studies (S1,S2,S3,S4)

Studies 1, 3 and 4 used an ACT based intervention whereas study 2 used mindfulness techniques alone (including mindfulness of breathing, body scan meditation and mindful stretching). Study 1 found reductions in psychological distress (GHQ-12) after 6 hours of ACT training compared to those who received ABA training only in a subset of individuals who reported practicing techniques. Intervention group participants with higher pre-test levels of psychological distress had greater reductions in distress. Study 4 also found a reduction in general psychological distress using the same measure at 6 week follow-up after a 1.5 day workshop, with no concurrent change in perception of work stressors. Study 3 reported reduced psychological distress (also GHQ-12) at 3 and 6 months post intervention using the same protocol as study 4. When comparing scores one month prior to intervention and 3 months post, there were decreases in depersonalisation (also measured in study 1) and perception of work stressors. However, there were no changes on the Acceptance and Action Questionnaire or the Support Staff Values Questionnaire.

Study 2 found more mixed results from their 2 month intervention of 2 hours a week mindfulness techniques; along with an increase in positive affect (small effect size) in support workers, it was notable that they found increases in negative affect, negative emotional symptoms and perceived stress, immediately post intervention. Unfortunately this study did not include a long term follow-up.

Cognitive -Behavioural (S8), problem-solving (S6,S7,S9) and stress inoculation (S12):

Study 8 was one of the few studies to articulate a theoretical model and rationale for the intervention, employing cognitive-behavioural techniques aimed at reducing feelings of inequity between staff and the service users and the organisation. They reported decreases in emotional exhaustion at 6 and 12 months (small effect size), absence duration and deprived feelings (particularly in those with higher perceived social support) in the experimental group compared to controls within the organisation. The single study reporting the use of stress inoculation training (S12,

ranked 4th in quality) found reductions in Anger Inventory scores in the intervention compared to control group, with greater reductions occurring for males.

Studies 6, 7 and 9 all used a pre-intervention questionnaire (6 and 9 used the Demands/ Supports and Constraints (Rose, 1999) to structure the workshops. As the interventions were determined by questionnaire responses and subsequent discussions, each group's interventions differed.

Study 6 reported reduced anxiety and emotional exhaustion post intervention, along with reduced perceived demands resulting from resident interaction and work pressure. Reductions in exhaustion along with reduced perceived sources of stress were also found. Study 9 found reductions in anxiety and increases in perceived social support (effect size of 0.13, a non-significant result) and positive staff interactions with service users post intervention in the intervention but not the control group.

In summary, the ACT based studies reported promising results with all three showing reductions in psychological distress post intervention (one found improvements restricted to those who practiced) with medium to large effect sizes. One study found additional decreases in depersonalisation and study 3 continued to find effects 1 year post intervention. The quality ratings of these studies were reasonable, including the second highest scoring (S1) and two middle scoring studies (S3,S4). The results of study 2, (employing mindfulness techniques), was the only study to report negative changes post intervention of small to medium effect size, and as the highest quality paper, these results should not be discounted.

Stress inoculation training (notably published 15 years ago with no replication found) and equity based interventions showed promise, were of reasonable quality and have the benefit of being theoretically based. However further assessment of their efficacy is required before their use can be recommend. Interpretation of the findings from studies 6, 7 and 9 as a group should be done with caution due to the

heterogeneity of interventions, lower quality score for study 6 and insufficient information provided to calculate effect sizes. With this in mind, some support was found for their efficacy; the studies using a measure of burnout (S6,S7) found reductions in exhaustion, those measuring anxiety (S5,S8) reported reductions and reported sources of stress (S7,S9) were also found to decrease.

Discussion

Despite having a common aim of reducing stress in staff, the nine summarised studies took a wide range of approaches, in their conceptualisation of stress, theoretical orientation and locus of intervention. The results of this review provide some support for the use of interventions targeted at reducing stress in staff that support people with ID. All of the studies reported some positive changes in outcomes, mostly with small to medium effect sizes. It has been suggested that interventions targeting burnout are likely to take some time to take effect, particularly for the constructs of cynicism and professional self-efficacy (Innstrand et al., 2004). Therefore, insufficient follow-up length may explain the lack of significant change in these subscales in the reviewed studies. Only one study reported any negative changes post intervention (of medium effect size). The study design does not allow for identification of possible causes of these effects. Negative changes may reflect a general increase in stress within the organisation, however, in the absence of a control group it is not possible to substantiate this. In addition, when using techniques such as ACT or mindfulness, there may be an initial increase in awareness of psychological difficulties (Smith and Gore, 2012), and a subsequent increase in distress. Had study 2 involved a longer follow-up period, the participants may have developed their skills further and reported fewer negative symptoms.

With only three studies implementing similar methods, comparisons between intervention types are made tentatively. It is perhaps surprising that only one intervention was described as using cognitive-behavioural techniques, given the emphasis placed on cognitive appraisal processes in the widely used Lazarus and Folkman (1984) model of stress and coping, and the prominence of this approach in the wider work site stress management literature (Flaxman and Bond, 2010). The interventions labelled here as problem-solving had the advantage of providing the

opportunity for organisational level intervention components in addition to improving individual coping capacity. As a result, they may be seen as a more ethical approach (by not placing responsibility for change solely on the employees (Giga et al, 2003), and a necessary part of any intervention given that organisational factors have been found to be the most reliable predictor of burnout (Skirrow and Hatton, 2007). However, the limited number of studies focusing on organisational factors (perhaps due to the increased complexity of organisational level evaluation) found in the present review preclude any conclusions being drawn regarding the relative efficacy of these intervention types.

The ACT based interventions are the most recently published but despite some promising results in this area, the evidence base is still in need of development. The reduction in psychological distress found in the study by Noone and Hastings (2010) was not accompanied by a change in perception of work stressors, consistent with the ACT model, in that psychological flexibility may increase well-being, without the need to reduce their perceptions of stressors. However, one study reporting a decrease in stress did not show concurrent changes in process measures (Smith and Gore, 2012), leading to uncertainty regarding the mechanism of change.

It has been proposed that pre-intervention distress might moderate the effects of interventions (Bunce and Stephenson, 2000), and this has been supported by findings of some more recent intervention studies in other staff populations (e.g. Flaxman and Bond, 2010). This hypothesis was not explicitly tested by any of the included studies (one study (Brooker et al., 2012) screened for depression, but as a safety measure only). However, two studies reported increased improvements in distress in those with higher pre-intervention distress (Bethay et al., 2012, Noone and Hastings, 2010), in line with the results of an early review (van der Klink et al., 2001) which reported larger effect sizes in studies targeting distressed workers compared to studies which did not include pre-intervention distress criteria.

The heterogeneity of the reviewed studies made integration of findings difficult. Outcome measures varied substantially, with a total of 21 measures being used. As discussed, the definition of stress includes both perception of stressors and the

effects of stress in terms of distress, anxiety and depression. Therefore, the measures used in these studies are likely to be tapping into a variety of psychological constructs that potentially have differing contributing factors and, as a result, may indicate the use of differing interventions. Additionally, the studies were published over a considerable time period. As working contexts change there are potential implications for the most effective way to reduce stress; as Thompson and Rose (2011) comment, changes in service context may be responsible for the apparent reduction in levels of burnout. In addition, those who have discussed the conceptualisation of stress and burnout (e.g. Innstrand et al., 2002), note changes over time and consequential changes in its measurement, also highlighting difficulties with combining the results of studies published over 3 decades.

The issue of clinical significance, or meaningful change (Bunce and Stephenson, 2000) should also be borne in mind when considering study findings. Almost all studies reported at least one statistically significant improvement in outcome measures post intervention, suggesting an improvement in well-being for the participants. However, the difficulty of assessing clinically significant change for interventions open to all employees (i.e. how to determine the amount of change required to be deemed clinically significant) has been raised (Flaxman and Bond, 2010) and would apply to all studies in the current review.

Evaluation of evidence base

The quality of the studies was variable. There were no randomised controlled trials and a lack of well controlled studies with large sample sizes and long term follow-up. Issues of replication and generalisation are frequently discussed in relation to intervention literature, including in the area of stress management. As Bunce and Stephenson (2000) note, details of participants and settings (four studies scored as 'well covered'), comprehensive descriptions of interventions (three scored as 'well covered') and thorough evaluation of fidelity (one scored as 'well covered') are necessary for these key concepts of research methodology to be fulfilled. In the present review only two studies (Brooker et al., 2012, Smith and Gore, 2012) were rated as 'adequate' or 'well covered' on all three aspects, highlighting the difficulty in judging ecological validity of the evidence base.

It has been suggested that development of burnout might be related to job role; (Thompson and Rose, 2011) differences in stress levels between support workers and managers have been found in some (e.g. Rose et al., 2000), but not all studies (e.g. Hatton et al., 1999). Therefore, the inclusion of mixed populations is a limitation to the evidence base in this area, as has been noted in the wider stress intervention literature.

In returning to the recommendations from Churniss (1980) and Rose and colleagues (2005), a number of comments can be made. Firstly, studies were not described as being within the context of wider stress reduction efforts, although given the context of intervention evaluation, this is perhaps justified in order to reduce confounding variables in the evaluation process.

Secondly, with the exception of the ACT and equity based interventions (van Dierendonck et al., 1998), studies did not discuss the theoretical basis for their interventions or include measures of process. This makes inferences regarding the mechanism of change difficult to make, particularly for interventions with components involving both individual and organisational change (e.g. Rose et al., 1998b) or when participants within the intervention sample received differing interventions (e.g. Innstrand et al., 2004). Others have also commented on the lack of theoretical integration in this area of research (e.g. Hastings, 2010) and it has been suggested that when theories of stress are used in this field, they are often out of date with the current work stress literature (Innstrand et al., 2002), criticisms which also apply to the current review findings.

Review limitations

The lack of inclusion of unpublished interventions and those published in a language other than English are limitations to this review. Within published articles there is a commonly discussed 'file draw effect' (Rosenthal, 1979) which could have a marked effect on the findings of this review. The inclusion of studies of mixed

populations could be described as a limitation to the review; however, as discussed above, this is common characteristic of the literature in this area. In addition, In the case of the inclusion of managers, it has been suggested that their participation is an important aspect of any successful stress management intervention (Giga et al., 2003) and as such, their inclusion could be justified.

The quality assessment tool used was developed for the purposes of the study, which could be seen as a limitation. Additionally, studies were given a total score to provide an indication of relative strength; however a note of caution must be applied as the 16 criteria do not have equal importance when assessing study quality.

Conclusions and implications for research and practice

The results of the current review suggest that the evidence base for stress reduction interventions for staff working with adults with ID contains great variability and significant methodological limitations. Some initial support for both problem solving type interventions and ACT based interventions was found, however, there is a need for well controlled comparisons of interventions before firm conclusions can be drawn, and further investigation into the negative findings of the mindfulness based study.

The current review highlights the need for further research to identify which stress reduction interventions work best under which conditions; a finding also reported in a review of interventions for parents (Hastings and Beck, 2004). The assessment of methodological quality highlighted a number of areas for potential improvement including: more rigorous sampling strategies, use of power calculations, greater use of control groups, inclusion of measures of process, measurement of fidelity and better management of attrition. Additionally, only two of the studies included a measure related to service user outcome; measuring a wider range of outcomes for staff and service users would add to our ability to evaluate the value of such interventions. Further areas of potential relevance include the relationships between service users and staff member, and how this may affect well-being in both groups

(Hastings, 2010) and the inclusion of more positive emotions (Devereux et al., 2009a).

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Chapter 2: Journal article

Waving a Magic Wand: Expectations of Support Staff in Intellectual Disability Services

Abstract

Many staff teams supporting adults with intellectual disabilities who display challenging behaviour receive input from clinical psychologists external to their organisation. Despite the complexity and importance of this topic, little primary research has been conducted with staff teams regarding this process. The present study used grounded theory to explore the experiences of staff working with clinical psychologists in the development of support guidelines for challenging behaviour. Nine support workers took part in individual interviews. The resulting model centred on expectations staff had regarding the input they would receive. Two differing sets of expectations were identified: the hope that clinical psychologist would ‘wave a magic wand’ and provide solutions to difficulties faced, or the desire for ‘negotiating a path’ with the clinical psychologist, involving the recognition of expertise in both staff and professional. The context for these expectations and components of these categories are discussed, as are the clinical implications of the model and potential areas for further research.

Keywords: intellectual disability, staff, collaboration, clinical psychology, grounded theory.

Highlights:

- Expectations are key to the experiences of staff working with clinical psychologists.
- Various contexts promote the hope of ‘magic wand’ being waved by the psychologist.
- Expectations and roles should be discussed before commencing assessment.

1. Introduction

Despite the significant changes in the support provided for individuals with intellectual disabilities (ID) over the past three decades, staff continue to play an important role in the lives of adults with ID (Hatton, Rose, & Rose, 2004). People with ID can display behaviour that is referred to as challenging; 'behaviour... of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion (Royal College of Psychiatrists, British Psychological Society, & Royal College of Speech and Language Therapists, 2007, p.14). Challenging behaviour includes behaviours such as verbal or physical aggression, self-injury or self-isolation and is displayed by roughly 10-15% of people with ID (Emerson, et al., 2000). The presence of challenging behaviour often necessitates input from professionals external to the organisation to support the staff team in promoting safety and minimising the occurrence of this behaviour. In the UK, the process of assessment and developing interventions and treatment packages often involves input from clinical psychologists working within the NHS with staff filling the role of 'mediators' (Willis & LaVigna, 1998) of these interventions. There is general consensus that advice from professionals, for example in the form of behavioural support guidelines, is not implemented consistently (e.g. McBrien & Candy, 2012; McGuire & McEvoy, 2007). However, there is a noted lack of direct measurement of staff behaviour in the literature (Hatton, et al., 2004). Levels of behavioural treatment integrity in other contexts such as schools has been reported to be as low as 4% (e.g. Wickstrom, Jones, LaFleur, & Witt, 1998). One of the few studies to directly assess intervention implementation in ID services used the Periodic Service Review (PSR, LaVigna, Willis, Shaul, Abedi, & Sweitzer, 1994), a tool measuring aspects of services and staff performance, including the management of challenging behaviour. This study found PSR scores were well below the acceptable minimum level of 80% (McKenzie, Rae, MacLean, Megson, & Wilson, 2006), and supports the suggestion that interventions are not always implemented as they were intended.

It has long been recognised that working closely with the people who deliver interventions is key to their success (Tharp & Wetzel, 1969). In addition, those

designing interventions need to assess the capacity of the system to implement the intended changes (Royal College of Psychiatrists, et al., 2007). A number of factors that may influence the support that staff provide have been investigated including: their experiences of stress (e.g. Robertson, et al., 2005), emotional reactions to and attributions regarding challenging behaviour (e.g. Dilworth, Phillips, & Rose, 2011; Wanless & Jahoda, 2002), treatment acceptability (Mccausland, Grey, Wester, & McClean, 2004) and organisational factors (Fyffe, McCubbery, & Reid, 2008). These factors all have the potential to influence the implementation of support guidelines.

Several authors have specifically addressed the barriers to implementation of support guidelines (e.g. Emerson & Emerson, 1987; McKenzie, MacLean, Megson, & Reid, 2005; Oliver & Skillman, 2002). For instance, Hastings and Remington (1993) suggested four main categories of barrier: 1. Service issues such as lack of resources, rules and regulations, lack of support for staff and lack of communication between staff. 2. The nature of the programmes, such as the perception of inflexibility of programmes and the use of technical language. 3. Problems associated with staff, including incompatible attitudes, a lack of knowledge and skills (e.g. over-protectiveness) and 4. External influences, for instance a relative's behaviour that is inconsistent with the principles of the guideline. These are all important issues to be considered when designing an intervention. However, there is a notable lack of reference in existing research to the process of guideline development and to the relationship between support staff and the professional with whom they work.

Best practice guidelines from the Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists regarding working with people with challenging behaviour states: '[There is] a mismatch between the expectations of professional staff and of staff providing direct support to individuals in community settings' (2007, p.10). The guidelines suggest that staff feel professionals do not understand their working context and in turn, professionals report that staff are not able or willing to implement the tasks given to them. Despite this and other conceptual-level discussion regarding working

with staff teams (e.g. Corrigan, Steiner, McCracken, Blaser, & Barr, 2001; McBrien & Candy, 2012), very little primary research has directly focused on the experiences of support staff working with professionals in the field of ID. Rose and colleagues (2006) describe the results of a questionnaire study in which they developed the 'Care Staff

Attitude Questionnaire', assessing the attitudes and experiences of staff working with external professionals. The scale was developed using a combination of material from a focus group and the experiences of the authors. It contains 20 items covering a range of appraisals made by staff including the professional's interactions with the support workers (such as being approachable and listening to them) and practical aspects of the input (including time spent with the service users and speed of response). However, as the development of the scale is not the focus of the paper, the description of the data collected from staff is brief and does not, therefore, provide an in-depth picture of their experiences.

Despite the lack of research in this area, findings of studies in related areas can shed some light on the current topic. In their discussion of 'mediator analysis' Willis and LaVigna (1998) suggest expectations that the person displaying challenging behaviour will be taken to Behavioural Services to be 'fixed' can interfere with implementation of treatment guidelines. Woolls and colleagues (2012) used a grounded theory approach to investigate the enabling and problematic elements of implementing Positive Behaviour Support (PBS) from the point of view of direct care staff and behaviour specialists. One of the core concepts from the support staff interviews concerned aspects of 'external support' from clinicians. Clinicians spending time with the service users and staff feeling involved and supported by the clinicians were found to influence the success of support guidelines. Whitworth and colleagues (1999) conducted interviews with five staff in a residential unit for people with severe ID and challenging behaviour regarding how informal rules govern their day-to-day work. They suggested that rules based on personal knowledge take priority over rules that are externally imposed (e.g. in the form of support guidelines) and interestingly, professionals were found to have less influence over staff behaviour than custom and practice which staff teams had developed as a collective. Involvement in the planning of interventions has been highlighted by

support workers as key to successful joint working (Windley & Chapman, 2010); suggestive of a more of a collaborative form of working relationship.

The theme of collaboration is relevant to a range of health and social care contexts; nearly 30 years ago an influential book was written entitled 'Meetings between experts' (Tuckett, 1985), which suggested medical consultations should be seen more as an interaction and less of a meeting with an expert. The topic of collaboration has also been discussed in relation to intervention for issues other than behavioural difficulties, for example Speech and Language Therapy (SALT) input. Graves (2007) used a 'grounded theory framework' to analyse interviews with both carers and SALT professionals regarding the factors that influenced implementation of interventions. One of the factors highlighted was 'collaboration and support for implementation', however many of the carers did not feel they had a 'relationship of equals' (p.117). Collaboration is also commonly discussed in relation to external professional input in schools (e.g. in the Journal of Educational and Psychological Consultation). Perhaps unsurprisingly, given the range of contexts to which it applies, collaboration has been defined in many ways, with differing emphasis placed on the nature of the joint input, who has responsibility for outcomes and how structured the processes are (Schulte & Osborne, 2003). The work of Hornby and Aitkins (2000) discusses various aspects of collaborative practice, highlighting the need to consider a range of interpersonal, structural and organisational conditions including professional stereotypes, support from colleagues and managerial structures.

Motivation to carry out the current study was driven by the clinical experience of the first author while working with staff teams within ID services. As the previous discussion illustrates, there is a lack of relevant primary research in this area. However, research in other contexts highlights the relevance of the working style of external professionals and their relationship with staff to the implementation of guidelines. The aim of the present study was to increase our understanding of the experiences of support staff in the field of ID working with clinical psychologists, for example, on the development of support guidelines for adults that display

challenging behaviour. Grounded theory was used to explore the factors that contributed to and shaped these experiences, and to create a conceptual framework which could be drawn on by clinical psychologists to support their clinical practice. An additional aim was to provide a potential starting point for future research.

2. Method

2.1 Design and theoretical background

The use of a qualitative method, more specifically that of grounded theory, was deemed most appropriate in light of the study aims and lack of previous research in the area. Grounded theory has been said to enable the creation of “conceptual frameworks or theories through building inductive analysis from the data” (Charmaz, 2006, p. 187). Individual, semi-structured interviews were chosen as they fitted with the aim of seeking individuals’ understanding of their experience of working with professionals and allowed interviews to cover the areas of most significance to each individual.

An interpretivist stance was taken, influenced by the work of Charmaz (2006) as this fitted with the first author’s epistemological position. The first author was a Trainee Clinical Psychologist in the final year of training, undertaking a placement in a Community Learning Disability Team, after having had previous experience in supporting roles with people with ID. Close attention was paid to the ways in which previous experiences influenced the interpretation of the data. In line with the constructivist viewpoint, recognising that it was not possible or desirable to ignore these influences, they were used to increase sensitivity to categories and their properties. The resulting model is one of many possible interpretations of the data, influenced by the context of the participants and interview process.

2.2 Recruitment

The project was granted ethical approval through the first author’s educational establishment. Purposeful sampling was used; service managers of private and charitable service providers were contacted to invite their teams to participate in the

study. Managers were asked to identify support workers who were fluent in English, had at least 4 months experience of supporting an adult with ID and had experience of working with clinical psychologists out with their service. All potential participants were given written information regarding the study which was discussed either at a team meeting or on an individual basis. Staff who were interested in participating gave their details to their manager or made contact directly. Prior to the interviews the information sheet was reviewed and participants were asked to sign a written consent form which informed them of their right to withdraw, anonymity and how the data would be used. Participants were also informed that any adult protection issues that arose during the interview would be reported to the relevant people.

2.3 Participants

A total of nine staff from three service providers were interviewed: two men and seven women. One service provided 1:1 support within a day support resource, the other two services supported adults within their own, or service owned homes in the community. Participants offered a range of support to service users, from 2 hours per week to 24 hours a day. Their length of experience in a support role with adults with ID varied from 1 to 10 years. Their ages (recorded in bands) ranged from 16-25 to 45-55. Participants described themselves as White British.

Participants described a number of conditions in which input from clinical psychologists occurred. Some had experience of the psychologist as the sole professional involved, for others the psychologist provided input alongside other members of a multi-disciplinary team (MDT); either a Community Learning Disability Team or specialist Challenging Behaviour Team. Three participants had experience of working with more than one psychologist. Participants from within the same service may or may not have been describing experiences of working with the same psychologist; to maintain confidentiality participants were asked not to provide names.

2.4 Data Collection

Interviews were carried out at the location of choice of the participants, either at their company office or in some cases at a local community centre. An atmosphere

of trust, acceptance and mutual respect was strived for during interviews to support the gathering of rich data (Taylor, 2005). Prior to interview they were asked to complete a questionnaire to collect background information. Semi-structured interviews were carried out using an interview guide which was revised as areas of interest were generated within the interviews. Participants who had previous involvement from MDTs were asked to focus on their experiences of working with psychologists. Initial questions were open ended (e.g. can you tell me about your experiences of working with clinical psychologists) to allow participants to facilitate the emergence of unanticipated issues or experiences. Follow-up questions were used to explore and clarify what was raised. Interviews lasted from 41 to 95 minutes, and were conducted over a 2-month period. Interviews were audio-taped and transcribed verbatim with any identifying information removed. To protect the identity of the participants and to ensure anonymity, each was allocated a participant number.

2.5 Analysis

Data collection and analysis were conducted concurrently. With each level of analysis the data was studied with increasing abstraction to allow for theoretical understanding that was constantly grounded in the original data. Analysis began with coding of the interview transcripts, the attaching of labels to segments of data to give meaning to the text, to sort it and allow for later comparisons to be made. Line by line coding was used to “keep close” to the data (Charmaz, 2006, p.94) and allow for the generation of many initial codes. Following on from this, focused coding enabled the researcher to provide an explanation for large sections of the data using and expanding on the initial codes that made ‘most analytic sense’ and categorised the data in the most accurate and complete way (Charmaz, 2006, p.97). Comparisons were continually being made both within and between participants’ data. Theoretical sampling within interviews was used towards the end of analysis to explore the emergent themes in the data (Charmaz, 2006). Cases or incidents that did not fit the emerging processes or were in contrast to other participant statements, termed negative cases, were sought out and used to expand evolving categories or to create new categories. A conscious effort was made to remain open to new insights and the possibility of making alterations to previously identified relationships or concepts. Discussion with colleagues allowed

for the identification of areas that required greater analytical elaboration. Theoretical sufficiency (Dey, 1999) was achieved when properties of theoretical categories were expounded, and no significant new theoretical insights occurred that required modification to categories.

Diagrams were used extensively in the development of the model, to help visualise links and compare categories with the extant literature. Paper based methods were used for coding and sorting. Memos were written throughout the process and a reflective diary was also kept to record thoughts, feelings and analytical insights. Therefore, an audit trail was kept of decisions regarding method and the progression of analysis.

The researcher used the principles of quality in qualitative research to guide the research process. Quality can be assessed at the micro and macro levels (Weed, 2009). Micro level analysis asks questions such as; does the study meet its own goals and does it have quality as an independent study. Macro considerations include: the use of an appropriate of methodology to the research question, explicit statements regarding philosophical position and contribution of research to the knowledge base. The first author was aware of the need to maintain a coherent methodology in line with her philosophical position, something that has been a criticism of some studies claiming to use grounded theory (e.g. Weed, 2009). However, it is acknowledged, as Dey (1999) suggested, there are as many versions of grounded theory as grounded theorists.

3. Results

Central to participants' experiences were their expectations regarding the input they would receive. Many participants described the hope that the professional would '*wave a magic wand*' and provide a set of guidelines that would give them the solutions to the difficulties they faced. Some spoke of these expectations retrospectively; these participants now held a different set of expectations focusing on the role of *negotiating a path* jointly with the clinical psychologist. They reflected on their transition between these two positions as a process of *finding their feet* and with that, the realisation that the existence of a 'magic wand' was not a reality. In

the negotiation of a joint path there was still a role for the clinical psychologist in *enhancing the practice* of the staff, however this was in the context of *recognising expertise* in the support workers and *giving suggestions* as opposed to instructions. Although not all participants spoke of needing a ‘magic wand’ to be waved, these responses (negative cases) were used to increase the theoretical conceptualisation of the data and categories.

The resulting model can be seen in Figure 1 below.

The adults with ID were referred to as ‘service users’ by the majority of the participants, therefore this term will be used for the remainder of this article. Terms in italics denote categories and sub-categories. Categories in quotations are in-vivo categories (i.e. those taken directly from the participant data) and those underlined are the more abstract, theoretical categories. The numbers in brackets at the end of the quotations indicate the participant number and the page of the transcript.

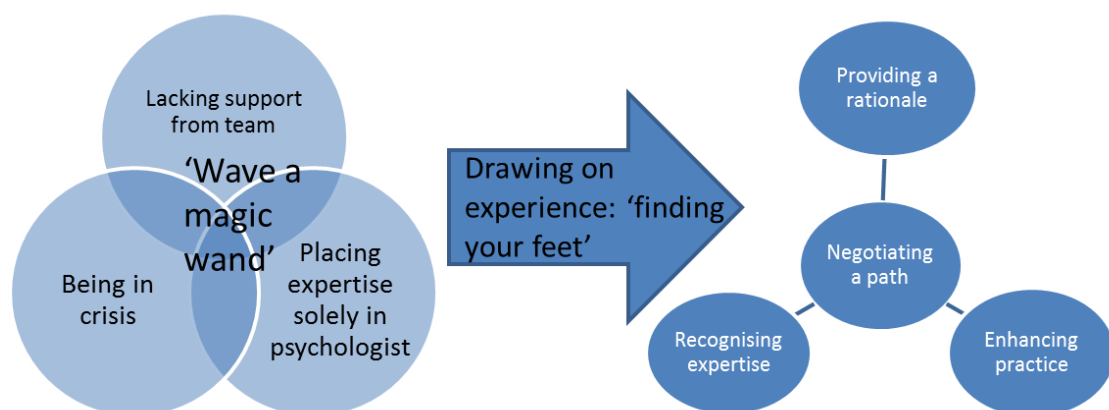


Figure1. Model depicting the expectations regarding clinical psychology input.

'Wave a magic wand'

In wanting the clinical psychologist to '*wave a magic wand*' participants looked to the psychologist to provide solutions to the challenges of supporting adults with ID. There was an expectation that a 'right' answer existed; 'Someone with the expertise will come and tell you the right thing to do' (1,9).

This desire for the clinical psychologist to wave a magic wand was heightened in the context of *placing the expertise solely in the psychologist*, lacking knowledge regarding the role of a clinical psychologist, feeling isolated or *lacking support from the team* and *being in crisis*. Those who did not experience these contextual factors were less likely to ascribe to the expectation of a 'magic wand'.

Placing expertise solely in the psychologist

The expectation of a 'magic wand' occurred in the context of participants placing the clinical psychologist in a position of expertise; as the ones with the knowledge.

'He's done it for years and has lots of experience, he knows so much more than I do, I think I wouldn't even question it at this stage' (3,11).

'They [the psychologist] will just know what to do (...) they are the ones with the expertise and knowledge' (4,22).

It was interesting that, despite seeing this expertise in the clinical psychologist, there was a lack of a clear understanding of their role; one participant described it as 'a bit of a mystery' (8,15). This lack of knowledge regarding how the clinical psychologist would work with the team resulted in ambiguity about what to expect and allowed for the hope and expectation of someone resolving their difficulties to remain.

'I wasn't sure what to expect really, on how the work would go, no one had told us. Maybe they would come and fix it for us' (7,3).

The origins of placing the expertise in the clinical psychologist, lay partly in the participants feeling that they lacked knowledge and skills, which led them to look to others for the solutions. Many reflected on their first few weeks or months in their job, and of *feeling unprepared* for their role.

'I wasn't ready for it....I think you need to know what you're going into first, so you are prepared' (6,22).

When participants were new to their post they often felt they had not been well prepared and were daunted by the position they found themselves in. For some this was linked to feeling they were *lacking in training*.

'You only get that one shadow shift and your away, and that's it, and for someone without much experience, quite a daunting thing' (5,14).

'The type of training the support workers get, to be honest it's not ideal (...) I didn't get any certified training for three years (...) it's not easy to start with' (2,9).

Participants who described feeling they were unprepared, lacked experience and training, described beliefs that resonated with the concept of low self-efficacy (Bandura, 1978).

'I had no confidence, I didn't think I knew what to do, or how to manage' (4, 21).

Feelings of low self-efficacy provided the context to participant's desire for input from the clinical psychologist; in the face of not knowing how to manage in the context of challenging behaviour, participants felt they required the psychologist to tell them how to respond to the service user's behaviour.

'We felt that we were completely floundering, and we didn't know how we could manage it, or what to do, so we wanted the professional to tell us what to do' (1,3).

The view of the clinical psychologist as the expert was particularly prominent in the participants who described their organisations as having more *traditional hierarchal service structures* (as identified by Praill & Baldwin, 1988). Decisions tended to be imposed from above rather than as a result of a two-way process of negotiation and consultation and support workers were not commonly involved in the decision making or development of in-service guidelines.

'Because *I'm just a support worker*, I've never had a say in the guidelines, these decisions are made well above our heads' (2,1).

For these participants who lacked confidence in their own skills and knowledge, not having had the opportunity to contribute to guidelines appeared to reinforce the feeling that they did not have the required expertise. This is also consistent with the concept of self-efficacy as performance outcomes (i.e. previous positive experiences) are one of the most significant sources of self-efficacy (Bandura, 1978).

The model proposes that lacking *rules to guide behaviour* and an *alternative source of information* are key to the expectation that the clinical psychologist would 'have

all the answers' (4,22) and be able to *wave a magic wand*. Two participants did not have the expectation of a magic wand, despite the presence of various contextual factors (represented by the categories *being in crisis*, *lacking support* and *uncertainty of professional roles*) that would support this expectation. These negative cases can be understood by the existence of another set of rules to guide these participants' behaviour and remove the need for the 'expert' to be capable of providing them with such rules. Hastings and Remington (1994) describe two types of verbal rules that govern both support staffs' explanations of challenging behaviour and their own behaviour; externally derived and self-generated rules. Externally supplied rules are derived from staff culture (which are passed on to new staff verbally and through observational learning) or come directly from support guidelines regarding challenging behaviour. Self-generated rules come from within and include an individual's beliefs. As an example, one participant was confident in their own way of understanding the service user. Therefore, when they received input from a professional that was judged to not fit with their understanding, their attitude towards this input and the need for additional support appeared to be more dismissive.

'They are good, listening to their point of view, but with Y, (...), everything is different.

To me it is more that she is just so spoilt (...) she's like a spoilt child' (6,15).

In this case, the participant's self-generated rule (based on her experiences of the family setting and child rearing), guided their thinking regarding the service user and therefore they were less motivated to receive input from the psychologist.

Lacking support from team

For many participants, in addition to feeling that the training they had received did not prepare them for managing the challenging behaviour and distress of service users, there was a perceived lack of support from within their team.

'You have to have lots of support, and I felt I didn't have it, from the team or managers' (6,19).

For some, the geographical configuration of the service lead to infrequent contact with team members and as such was an additional barrier to receiving support. For

one participant who supported individuals in their own houses (which were spread out over the city) there was a real feeling of isolation;

'No one is there for you. You're on your own' (5,15).

Lacking experience and *working in isolation* from colleagues led to some participants lacking a source of rules regarding how to respond to challenging behaviour. This increased their desire to be told what to do and for the clinical psychologist to 'rescue' them. Negative cases were used to elaborate on the impact of support from the team on participants experiences. For those with colleagues nearby and with high levels of cohesion with the team, there was a sense that they were more able to manage difficult situations with less need for external support.

'I was nervous working with the service users, but I had enough information to go on. I think it was because I had a good team to work with. They always just said if you have any issues just give us a holla' (3,1).

As a result of this alternative set of rules by which to guide their behaviour, there was less of a reliance on clinical psychologists to supply them with rules in the form of behavioural guidelines.

'We have our own policies, and we get together to work it out, so only when they are not effective and we are not getting anywhere with it, that when we would contact the challenging behaviour team, only if we really needed it' (7,7).

Hastings and Remington (1994) suggested rules derived from informal staff culture are often more influential in determining staff responses than formal guidelines or input from team managers. This is because the contingencies for the cultural rules are more powerful and salient; the individual is regularly rewarded for continuing to behave in such a way. Therefore in these cases guidelines may be seen as unnecessary complications presumed not to work (Hastings, 1995), consistent with the previously mentioned study by Whitworth and colleagues (1999).

Being in crisis

As might be expected, in all cases the clinical psychologists were asked to provide input for service users at times when there were concerns about their behaviour or mental health. However, when participants experienced situations where the challenging behaviour had quickly escalated, this contributed to the hope that the clinical psychologist would be able to tell the participants how to manage.

‘Her behaviour really dipped, her mood really dipped, we needed constant involvement from the challenging behaviour team’ (4,1).

‘It was an emergency referral, of a woman who had to leave her family home, in, uh, exceptional circumstances, and, she presented with quite challenging behaviour (...) it was such an intense time (1,2).

Participants described feeling the behaviour was getting to such a frequency or severity that it could not continue and as such, created urgency for the solution to be found.

‘The behaviour had got to the point that I didn’t think we would be able to keep the service’ (2,4).

‘Finding your feet’

There was recognition from those with greater experience, that over time they were able to ‘find their feet’ in their role. This allowed them to feel increased confidence in their own knowledge, skills and understanding of the service users. This change was seen partly as a result of the passage of time, through *persevering*; ‘you get there if you just keep going’ (5,15).

‘*Finding your feet*’ was also reflected on as a result of more active processes such as *learning from mistakes*; in managing a situation in a certain way and later reflecting that perhaps there were better ways to respond.

‘I’m much more on the ball now, I wasn’t when I started, but I have learnt that from making mistakes’ (5,14).

These experiences of *learning from mistakes* were seen as particularly powerful in changing practice;

‘That’s when my eyes were open with X, and I thought, well I’ve got to deal with it differently’ (6,4).

This change over time was related to a change in expectations regarding clinical psychologists and what they could offer. Those who had worked with a number of clinical psychologists were able to reflect on the changes in the way they approached the input. They spoke of their initial expectations not being fulfilled;

‘I had thought they would just know what to do (...) but I learnt that wasn’t what happened’ (4,22).

They described having learnt over time that these expectations didn’t reflect the reality of working with clinical psychologists and as a result they had had to alter the way they approached referrals to external professionals.

‘Next time I would come prepared with what I wanted, with questions, as I suppose my first experiences, I suppose it was the naive hope that, and then I was disappointed that they didn’t, I wanted them to rescue us, but I expected too much’ (1,10).

Negotiating a path

Those who had gone through the process of ‘finding your feet’ had greater awareness of what they had to contribute to the development of guidelines. They spoke of wanting there to be negotiation regarding the input, more of an interchange between the support workers and clinical psychologists. Although none of the participants used the term, they seem to be referring to collaboration. As a basis for this there was a desire for increased clarity on what each party would contribute.

‘There can be a better understanding on both sides of what both sides are able to offer’ (1,10).

Part of *negotiating a path* was about getting to the position of *knowing where you are* and *having a shared goal*.

'I would like a two-way discussion, to know what will happen... [otherwise] it gets very messy and you end up going round in circles not knowing where you are' (8,9).

'Having a final goal is important, what the input will hopefully achieve (...) otherwise your just left in the dark a bit with the challenging behaviour, not knowing what's expected from you or what you will get from them' (9,5).

Creating and working towards a common goal is a key part of many definitions of collaboration (e.g. Hornby & Aitkins, 2000).

When describing a clinical psychologist who had what appeared to have an authoritarian style, one participant said;

'It can feel more like being told what to do rather than working together on a problem' (8,6).

Recognising expertise

Recognising expertise was identified as a key part of *negotiating a path* with the clinical psychologist. There was an expectation that the psychologists would be open to the opinions of the support workers; *being heard* was seen as key to this.

'They [the team and managers] do respect our views on it and take it all into consideration. And I would expect that from anyone else we got help from, so they can take all our views into consideration' (2,12).

Participants spoke of the part they could play in the process of guideline development and knowledge they could contribute, the expertise did not lie solely in the clinical psychologist.

'You're an expert in certain ways but you're not an expert in the person' (1,10).

Recognising expertise of both the support workers and the clinical psychologist could lead to the *combining of knowledge*;

'Take bits of everyone's input, put it together. That's all. It's almost like a jigsaw puzzle' (8,8).

This is in keeping with the 'equal but different roles' model of consultation (Jaques, 1947, cited in Schulte & Osborne, 2003) in which the differing skills and knowledge of the consultant and consultee are recognised and combined in what has been described as 'joint problem-solving exercise's' (Hartas, 2004).

However, despite this expectation, participants described situations where their expertise was not always recognised in the way they hoped.

'It was as if the information you were coming with was not really being taken on board' (8,4).

Enhancing practice

Perhaps unsurprisingly, participants still looked to the psychologist to give them new strategies, they wanted to be '*offered something new*'; 'We look for some new ideas, some different things to try' (9,4).

However unlike those with expectations of a magic wand being waved, it was acknowledged that often there was no right answer. However, this was seen as a reflection of the nature of the situation and not the fault of the psychologist.

'I wanted them to come up with the protocols that would work, but the longer I've been working with her I've realised that isn't always possible' (4,24).

The expertise of the professional was recognised in their *specialist knowledge* of certain areas and the *professional's past experiences*, allowing them to enhance the working practices of the support workers.

'If we need help with a specific thing, she knows that, that's her job to help us with that, they have that knowledge' (9,1).

The new information and knowledge that the psychologist was able to provide to the staff team was seen as valuable and capable of enhancing their practice. This 'cognitive gain' (Wright, 1996) is seen as one of the positives of collaborative working.

'It was helpful to know the exact extent of her cognitive disabilities....the psychologist was able to tell us things like that, made the team a lot more understanding in their approach' (1,2).

Input from the clinical psychologists was also valued for the '*space to think*' that it provided, something which wasn't always available in the busy working environments of many teams and has been previously reported as a factor that helped change staff's views regarding challenging behaviour (Whittington & Burns, 2005).

'Our meetings and putting the protocol in place have made us really think, more about your service user, a lot more in depth' (4,20).

Providing a rationale

The importance of the psychologist *providing a rationale* was highlighted as a central element of *negotiating a path*. Having a rationale was seen as increasing the knowledge of the support team.

'It [the rationale] needs to be explained to the support team. So that everyone realises the bigger picture, so that you can see the consequences for the staff coming after you' (2,2).

As part of the process of *negotiating a path*, the support guidelines provided by psychologists were seen as 'advice' to be considered, as opposed to instructions that had to be followed.

'It is advice. There is no obligation to take the advice, sometimes it's useful, don't get me wrong, sometimes not' (8,4).

Having a rationale for a support guideline or strategy was seen as increasing consistency in its implementation; the implication was that the advice was more likely to be followed if there was a rationale provided.

'Give us the reasoning behind why, cos there's no point in saying do this if we don't know why, we just won't do it' (9,4).

4. Discussion

4.1 Discussion of findings in relation to existing literature

The expectation of a magic wand was central to the conceptual framework developed in this study. The 'myth of the hero innovator' (Georgiades & Phillimore, 1975), a well-trained individual capable of single-handedly effecting change in an organisation, has been often discussed in the ID literature, commonly from the perspective of those instigating change (e.g. Praill & Baldwin, 1988). It would appear, however, that this view of psychologists is held by some support staff and has potential implications for the way they view their role when working with psychologists, for example, in guideline development. In Woolls' (2012) study regarding the implementation of PBS, clinicians identified high expectations of the intervention as a mediating factor in intervention efficacy; people with high expectations might be disappointed by the perceived lack of progress and this may impact negatively on their attitude towards it. The current findings reinforce the role of expectations, however it is interesting that in Woolls' study, the issue was raised by the clinicians but not the direct care staff.

The context for the expectation of a 'magic wand' was influenced by factors such as a lack of training, low self-efficacy and hierarchical service structures. That the participants lacked clarity regarding the role of clinical psychologists is perhaps not a surprise to clinicians, indeed, other professionals who arguably have more contact with psychologists have been found to be similarly unsure (Osborne-Davies, 1996). Many participants expressed dissatisfaction with the training they received, which has been reported previously (e.g. McVilly, 1997). It has also been suggested that a lack of understanding of the rationale of an intervention, partly due to a lack of training, is one possible source of 'resistance' to interventions (Tharp & Wetzel, 1969). In the current study, lack of training contributed to participants feeling unprepared for the challenging situations they faced, which then contributed to low self-efficacy and desire for the clinical psychologist to 'wave a magic wand'.

That low self-efficacy was highlighted as a contextual factor to the desire to be told what to do is supported by other research; high self-efficacy has been suggested to increase the likelihood that individuals would actively engage change processes and influence their course (Fugate, 2013, p.21). In addition, organisation and structural issues, such as those identified in the current study, have been noted to contribute to difficulties with carers working with professionals in other contexts (e.g. speech and language therapists, McCartney, 1999).

Woolls' (2012), Potts and colleagues (1995), and Whitworth (1999) highlighted the potential for support workers to have a perception of 'them and us' and to feel criticised by professionals. Whitworth (1999) uses Schein's (1996) description of the professionals as 'engineers' and staff as the 'operators' carrying out the tasks, who feel threatened by the interference of the 'engineers'. These feelings were not communicated by the participants in this study. It is possible they were wary of portraying a negative picture of their experiences, but this was not felt to be likely as participants did describe dissatisfaction with clinical psychologists; not due to feeling criticised, but from a desire for their expertise to be recognised. The timing of interviews may provide another potential explanation. Some participants, particularly those less experienced, had not spent much time working with clinical psychologists, therefore may not have experienced a threat to their autonomy and the subsequent defensive reaction that can result from overt attempts to change behaviour (Kelman, 1961). On the other hand, those with more experience of working with psychologists described having worked more collaboratively and as a result their appraisals were not of being criticised but of having a feeling of increased self-efficacy and having their views considered.

Negotiating a path shared many characteristics with the 'equal but different roles' model of collaboration (Jaques, 1947, cited by Schulte & Osborne, 2003). This model is suggested to increase implementation in a number of ways including; the increased ownership of the intervention from contributing to its development and through the increased self-efficacy resulting from individual's recognition of their own expertise (Schulte & Osborne, 2003). There is a lack of recent research regarding the increased efficacy of a more collaborative approach in the field of

adult ID services, however findings other areas are relevant. As Schulte and Osborne (2003) describe, the model of 'equal but different roles' was developed in light of evidence that involving people in decision making reduces resistance to change. For example, participation in decision making regarding a merger affecting hospital workers was found to be correlated with increased commitment to change (Sverke, Hellgren, Näswall, Göransson, & Öhrming, 2008). Additionally, when individuals are involved in decision making they are more likely to invest in the outcomes and contribute ideas regarding improved working practices (Anderson & West, 1996).

4.2 Clinical implications

When discussing ways of working with support staff and carers, McBrien and Candy (2012) suggest planning the implementation of an intervention is as important as the assessment, formulation and the guideline itself. The model arrived at within the present study indicates that even before these stages, the expectations of staff are key to their experiences of working with psychologists, and are likely to impact on the implementation of the intervention. Hornby and Aitkins (2000) suggest professionals must work on adjusting the balance of power. This is supported by these findings in relation to clinical psychologists; some participants placed the expertise in the professional and expected to be 'rescued' by the expert. Allowing the expectations of a 'magic wand' to persist is incompatible with the more balanced, negotiated path of collaboration, where the support workers are empowered to make a more substantial contributions to the process and resulting guidelines. The proposed model suggests a number of factors that influence the formation of these expectations, including the relationships and contact with the staff team, management style, existence of alternative rules to guide behaviour and self-efficacy of the individuals. Considering these during initial consultations may provide a better understanding of the context for the collaboration. An interesting aspect of *negotiating a path* was the view that the advice of the clinical psychologist did not have to be taken. The psychologist's attitude towards this issue is likely to differ between professionals and contexts, however, it is an issue that would benefit from being clarified at the start of the input, possibly in the form of a contract between the service and psychologist.

Discussion papers regarding working with staff teams (e.g. reports from professional development events such as Richie, 2009) provide key recommendations such as respecting the knowledge of the staff, focusing on what each person could bring and the maintenance of involvement leading to an on-going sense of investment from psychology. All these strategies were recognised by the participants as central to *negotiating a path* and as such, their use is supported by the current findings.

Other strategies that may facilitate *negotiating a path* are also implicated and are in line with the 'equal but different roles' model of collaboration. For example, as *being heard* was a key issue for participants, psychologists might consider introducing workshops to allow all staff to express their views and raise concerns (Rose, et al., 2006) and these could also provide an opportunity the clinician to reinforce staffs' recognition of their own expertise. In common with the findings of Whitworth and colleagues (1999), the participants indicated there were is a need for greater understanding and 'common ground'. As discussed by Graves (2007) in relation to SALT interventions, 'domain mapping' (Hornby & Aitkins, 2000, p.155), through which roles and responsibilities are defined and allocated, may be a useful tool to clarify expectations. As Hornby notes, this needs to be followed by the establishment of communication processes to ensure information continues to pass between all involved. This clarification of roles may be particularly useful for new staff with little of their own experience to refer to, however this also needs to happen at other levels of the system to ensure managerial support (as suggested in relation to SALT by Hartas, 2004). An alternative way to manage expectations might be provided by a different model of working for psychologists providing input to residential services. McKenzie and colleagues (2009) describe one such model where psychology graduates take a dual role as support workers and assistant psychologists under the supervision of clinical psychologists.

4.3 Research process, limitations and future research

The model generated is described as a substantive theory; one that is created within and is relevant to, a specific phenomena focused upon in an identified group of people in a defined context. Therefore, the applicability of this model is limited; clinicians must judge the similarity of their context to that of the study, and the extent to which the model and its implications are applicable to their work setting.

Various factors were identified that may have influenced the data and subsequent model generated. Two participants spoke of having a poor memory of some events that occurred some time ago. It is unclear how this impacted on their understanding and reporting of their experiences and it is possible that what stood out for them at the time of interview may be different to what seemed important at the time. Further research would be needed to clarify the effects of the passage of time on the reported experiences of working with professionals. Some participants in the study had only limited experience of working with psychologists in developing guidelines, which led to them being less able to provide rich data. In addition, the sample size was small and due to the recruitment method, it is possible that certain characteristics of staff were selected for. These factors indicate there may not have been as wide a range of experiences represented in the sample as there could have been, which might have influenced the ability of the researcher to fully expand categories and create a model that represents the full spectrum of feelings, attitudes and experiences. Due to the heterogeneity in the sample there was not a discrete set of experiences represented in the data, and as a result, some categories were less well expanded than others. Further interviews employing theoretical sampling could have led to refinement of categories and their properties; they were not fully saturated. The inclusion of theoretical group interviews (Morse, 2007) would have provided additional data for the analysis and potentially enhanced the richness and refinement of categories.

Participants' responses were influenced by their perceptions regarding their audience i.e. a Trainee Clinical Psychologist (Richards & Emslie, 2000). How this might have impacted on what the participants were prepared to say and how they wished to present themselves was considered throughout the analysis. However, in line with the philosophical position of the researcher, it was not considered possible to 'remove' this influence.

In light of these limitations, the model is acknowledged as tentative and open to revision in light of future research. Extending the study using a larger sample would be one way to evaluate the model, in further verifying the categories generated and the relationships between them and increasing confidence in the final model.

As noted above, it is hoped that psychologists will use the model and its clinical implications to inform their practice, creating an increased focus on the expectations of staff. Implementation of these strategies could be evaluated using a variety of

methods (e.g. individual interviews or written questionnaires), examining support staff satisfaction with their experience of joint working, in particular the management of expectations.

The effects of this expectation of a 'magic wand' on the interactions with clinical psychologists was not part of the model presented in this paper. However, it is likely it would have far reaching effects on relationships, which could be the focus of further research. It would also be interesting to extend the model and explore more fully how these expectations impact on the implementation of guidelines although it should be born in mind that interview data cannot claim to predict behaviour (Taylor, 2005). Conducting interviews with clinical psychologists would provide a fuller understanding of both sides of the interactions that occur between staff and professionals, as in some cases quite differing views have been reported from either side of working partnerships (e.g. Thomas, Sexton, & Helmreich, 2003).

4.4 Conclusions

When discussing their experiences of working with clinical psychologists on the development of support guidelines, participants highlighted the importance of their expectations regarding the input. The existence of the desire for a 'magic wand' to be waved and the psychologist to provide the answers to the difficulties faced was found to be heightened by the presence of a number of contextual factors. The alternative expectation of a negotiated path, while still leading to enhanced practice of the support workers, was supported by the recognition of expertise in all parties.

Despite the previously described limitations, this study provides novel insights into the experiences of staff working with clinical psychologists that have potential to inform clinical practice, although ultimately its utility will be judged by others.

5. References

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Chapter 3: Extended Method

To avoid duplication with the method section of the journal article, the following chapter is not a complete description of the study method. It will provide a rationale for the methodology and discussion of relevant issues such as ontology, epistemology and reflexivity, in a more in-depth way than space restriction allows for in the article.

3.1 Design

A qualitative approach was chosen. This is often the preferred method of research for topic areas where little previous research exist as it allows for generation of new insights (Corbin & Strauss, 2008), as opposed to the application of previously created hypotheses (as commonly seen in quantitative research).

A grounded theory approach was felt to be the most appropriate for a number of reasons. Firstly, due to the lack of research in the area, its exploratory in-depth nature was appealing to the author. In addition, it allowed for the creation of a tentative conceptual framework which could be used to elucidate staff experiences. It was hoped that the resulting framework will be useful for clinicians in their thinking regarding their clinical work with staff groups.

Individual interviews were used to provide a space to explore participants' experiences, insights and meanings associated with working with professionals.

There is not a 'typical' data collection method for grounded theory studies (Wimpenny & Gass, 2000). However, semi-structured, in-depth interviews are often used as they allow for the desired characteristics: 'open ended yet directed, shaped yet emergent, and paced yet unrestricted' (Charmaz, 2006, p.28) and as such were chosen for the current study. The general areas of interest were used to create preliminary questions (see Appendix 6 for interview guide), and the precise content of the discussion was left to be guided by each participant and altered as the interviews progressed (Charmaz & Belgrave, 2012).

Alternative qualitative approaches were considered. Interpretive Phenomenological Analysis (IPA) was one possible alternative method. IPA takes a micro level approach and offers a similar way to both capture what is happening within the data and to offer interpretation of the material (Larkin & Thompson, 2012). It requires a relatively homogenous population and, more recently, requires that coded themes have to appear in a percentage of the overall data for them to be included in the final analysis (Smith, 2009). In addition, it does not have the appeal of the creation of a conceptual framework that grounded theory offers.

Discourse Analysis has a focus on communicative interactions and commonly discusses how people's use of language relates to social problems (e.g. gender, race or the power dynamics in relationships, McMullen, 2011). There is a common focus on linguistic practices, with less importance placed on the individual's experience, perceptions and beliefs (Potter & Wetherall, 1987). For these reasons it was deemed to be a less appropriate methodology for the aims of the current study.

3.2 Ontological and Epistemological considerations

Grounded theory as a methodology stems from the work of Glaser and Strauss (1967). Since then, researchers, with a range of ontological and epidemiological positions, have developed a number of methods (procedural guidelines) and there is now a body of literature discussing and comparing these approaches (e.g. Heath & Cowley, 2004). There is no 'correct' method, however, whichever grounded theory approach is chosen, it should be informed by the philosophical position of the researcher (Birks & Mills, 2011).

Ontological position, the view taken regarding the nature of reality, can be seen as on a continuum from realist to constructivist. Unlike a strictly realist ontology, constructivist researchers do not subscribe to the view that there exists one reality made up of solely objectively defined facts. Reality is viewed as existing through the eyes of the participants and as such multiple realities are maintained. As Weed (2009) points out, certain ontological positions lead naturally to the corresponding epistemological positions; the view of the way that knowledge is acquired.

Epistemological positions can be placed on a continuum from positivist to interpretivist (Cohen & Crabtree, 2008). A positivist stance to qualitative research might suggest a researcher can bracket their experiences so that they do not bias their interpretation of the data. Whereas an interpretivist approach would argue that this is not possible and the way the theory is constructed is partly down to the experiences of the researcher; 'They (researchers) don't necessarily "hear" what their informants tell them but only what their own intellectual and ethical development has prepared them to hear' (Johnson & Rowlands, 2012, p.101). As a result, a grounded theory using an interpretivist approach is treated as one of many possible interpretations of the data and a way to generate working hypotheses as opposed to empirical facts. However, interpretivist researchers might still warn of imposing one's preconceptions and of ensuring a mind open to the possibility of revision of categories; an open mind does not equate to a blank mind (Dey, 2007).

As many texts regarding grounded theory suggest, (e.g. Birks & Mills, 2011) the researcher first spent time considering her position. The researcher aligned herself with a critical realist ontological position, commonly associated with the works of Bhaskar (1978). This view asserts that there are some realities that exist in the world, however they are independent of our knowledge of them. In observing these realities there is an inevitable influence of the person observing and these observations are in fact dynamic rather than static, and therefore open to revision (Oliver, 2011). Therefore, taking a critical realist position indicates that an interpretivist epistemological stance should be taken as the impact of researcher is inescapable and there is an acceptance that what is 'observed' is open to revision. The methodological approaches used by interpretivist researchers such as Charmaz (2006) also appealed as some other methods, for example of those of Strauss and Corbin (1998), were felt to be too prescriptive and risked forcing data into preconceived frameworks at the cost of excluding interesting phenomena that occur in the data.

Some grounded theorists use the term 'emergence', coined by Glaser (e.g. Glaser & Strauss, 1967), to describe the process by which categories are named within the data and the term 'discovery' in relation to theory. However, as has been noted (e.g.

Kelle, 2007), this suggests the categories exist within the data and are there to be found by the researcher (implying little or no influence from the researcher) which is in line with a more positivist stance. However, this is not consistent with the critical realist approach favoured by the author.

Both induction and abduction are used in the creation of a grounded theory (Bryant & Charmaz, 2007); induction when extrapolating from an individual to form a more abstract conceptual category and abduction when considering a range of theoretical explanations then returning to the data to assess which explanation fits best with the data. The term adduction is increasingly being associated with grounded theory as it stresses both logic and innovation (Reichertz, 2007). The term acknowledges the influence of the researcher's hypotheses and theoretical knowledge, the iterations between theory and evidence, and as such, fits closely with the position of critical realism (Oliver, 2011).

3.3 Reflexivity

Reflexivity is defined by Charmaz (2006) as: 'The researcher's scrutiny of his or her research experience, decisions and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher's interest, position and assumptions influenced inquiry' (p.188-189).

Researchers can be viewed as the sum of their experiences and as such are advised to reflect on this throughout the research (Birks & Mills, 2011). The researcher was a Trainee Clinical Psychologist in the final year of training, undertaking a placement in a Community Learning Disability Team. Previous experiences including supportive roles with people with intellectual disability, assistant psychologist posts within the NHS and private organisations and more recent role as a Trainee Clinical Psychologist all contributed to her interest in the topic of the project. The researcher paid close attention to the ways in which her previous experiences, attitudes and values were influencing the interpretation of the data. In recognising that it was not possible, or desirable, to ignore this influence, the researcher used it to increase sensitivity to categories and their properties. As discussed by Johnson and Rowland (2012), those with experience or knowledge of

an area are more likely to see the nuances of a situation. However, in line with one of the main tenets of grounded theory, that the categories and subsequent theory must fit the data, skill is required to strike a balance between using the knowledge and experiences of the researcher and maintaining fit with the data (Henwood & Pidgeon, 1992).

For ethical reasons the rationale for the project was made explicit to all participants (i.e. as part of the Doctorate in Clinical Psychology). In line with other researchers (e.g. Richards & Emslie, 2000), the author considered her status as a Trainee Clinical Psychologist to be an important aspect of the interview process. The researcher was working on placement in another geographical area from which the services were recruited so was not known to the participants in a professional capacity. However, she was reflective regarding the potential impact that her position would have on the participants and was aware that it could be a barrier to participation. The role of a trainee may be seen as different in the sense of being a student, but is still likely to be viewed as a 'professional' and this may have influenced the responses. One participant appeared keen to qualify his discussion regarding a negative experience with a professional by saying, 'that first part sounded negative. It's not all a negative experience', which could be seen as an attempt not to offend the researcher.

In line with recommendations by Mills and colleagues (2006) attempts were made to increase reciprocity in the research process. Interviews were carried out at the location of choice of the participants to give them greater control. The researcher was flexible regarding timings of interviews and made meeting at evening and weekends a possibility to attempt to fit in with the participant's work schedule and other commitments. She answered questions posed as honestly as possible and shared her understanding of the key issues after the interviews.

3.4 Data management

Paper based methods were used throughout the analysis in addition to basic word processing software. NVivo 8 was investigated as a possible specific qualitative data analysis programme, however, for a number of reasons the researcher

decided not to use it. Firstly, the use of a software analysis programme was not viewed as necessary. Such software was seen by the researcher as solely for the purposes of data management (as suggested by others, e.g. Kelle, 2004), because unlike quantitative software, the analysis, and most importantly the interpretation, is still completed by the researcher (Gibbs, 2004). Secondly, the time required to become proficient in its use would have been significant and this was not deemed a good use of the limited time available. Instead, time was spent at the start of the project deciding on procedures to ensure easy access to the data and increase consistency of the approach, two noted advantages of analysis software (Bergin, 2011). Thirdly, there is a reported tendency for the programmes to support more prescriptive forms of analysis (Robson, 2002), and this was felt to be the case by the researcher when investigating NVivo. For example, the tree nodes are organised in hierarchical fashion, which felt limiting and could have encouraged forcing of the data to fit this structure.

Prior to initial coding, the interviews were listened to multiple times and subsequently read and re-read. This allowed for notes to be made regarding the prosodic features of the interviews, created familiarity with the content and began the process of conceptualisation of the data. Interviews were transcribed verbatim into word processing files, each containing three columns. The interview text was contained in the middle column, the right hand column was used for initial line-by-line coding and the left column for early conceptual ideas and focused codes. The initial codes were transferred to colour-coded, numbered post-it notes according to conceptual similarity. These were then arranged and re-arranged on large pages of paper, in a similar way to a mind-map in order to visualise connections and relationships between codes. Memos were written to record definitions of categories and their supporting quotes, given numbers to match those on the post-its and kept in a ring bound folder for ease of access. Other memos were used to support the research process by aiding the researcher's reflection, making explicit the researcher's interpretations and reactions to the data and clarifying the development of thinking; increasing transparency in relation to the analysis. Every alteration to a diagram, code or memo was dated to allow for tracking of changes in conceptualisation of the data. The constant comparative method entailed re-reading the transcripts at all stages of analysis and as a result, ensured that initial codes and notes were kept in mind as the stages of analysis progressed. Discussions with supervisors regarding the categories and their supporting quotes ensured they were

grounded in the data and allowed for the identification of areas that required greater elaboration or refinement.

3.5 Use of the literature

A pragmatic approach was taken to the use of the literature as discussed by Bluff (2005) whereby a review of the literature was conducted prior to the start of the project sufficient to ensure no such other project had been conducted and to develop a rationale for the method. Literature was then used once the model was taking shape in order to refine ideas and provide additional data for comparison.

3.6 Ensuring Quality

The philosophical position taken by the researcher affects the view taken regarding the assessment of quality and rigour. The traditional positivist criteria of validity and reliability have been argued to be inappropriate in the context of qualitative research, particularly when taking an interpretivist slant. The focus on removing bias from a study using the experimental paradigm is no longer applicable when the researcher is seen as part of the process of generating the knowledge (Henwood & Pidgeon, 1992). Although those taking the approach of 'subtle realism' might argue that all research requires 'subjective perception' and as such can be compared using the same criteria (Nicholas & Catherine, 2000, p.51), others have developed separate criteria to assess the quality of qualitative research. One such set of criteria is that of Yardley (2000) who proposed four criteria; 1) sensitivity to context; 2) commitment and rigour; 3) transparency and coherence and; 4) impact and importance. Given the variety in qualitative approaches, some have suggested an advantage to assessing quality and rigour in ways that are specific to the method (e.g. Chiovitti & Piran, 2003) and this approach was taken by the researcher.

Weed (2009) identified eight core elements that must be fulfilled in order for a study to be considered to be using grounded theory, and as such can be used as criteria by which to judge the quality of a study. The researcher used these criteria to guide the process from design of the study to writing up.

The elements are:

- 1) An iterative approach; data was collected and analysed concurrently.
- 2) Theoretical sampling; data was sampled according to concepts/ areas that arose during analysis.
- 3) Theoretical sensitivity; the researcher acknowledged they began the project with an awareness of the topic area and used this as a place to begin to look at their data.
- 4) Codes, memos and concepts; analysis begun with more descriptive coding of data and through the use of memos, later stages looked to conceptualise the phenomena of interest through the use of more abstract concepts.
- 5) Constant comparison; comparisons were made throughout the analysis between data, codes, concepts and literature.
- 6) Theoretical saturation; data gathering and analysis stopped when the analysis ceased to lead to new insights or alterations to concepts.
- 7) Fit, worth, relevance and modifiability; Constant comparison ensured a close fit between the data and the concepts generated. The way the interview was described to the participants (i.e. as a place for them to discuss issues that were important to them) and the general open ended questions of the interview ensured the issues discussed are kept relevant to the people involved. The researcher acknowledges that the resulting theory is modifiable; it is open to revision in the light of new data or insights.
- 8) Substantive theory; the theory generated is grounded in the area in which it was developed; the researcher does not claim that it is generalizable to other areas. Extensive research in many other substantive areas would be required to raise the theory to a formal theory.

3.7 Ethical considerations

The project was reviewed and granted ethical approval by the Edinburgh University School of Health in Social Science ethics committee (see appendix 5).

Completing the informed consent checklist with the participants ensured they were aware of their right to withdraw, how their data would be stored and the steps taken to anonymise the data. Some participants were offered the opportunity to participate via their managers as it was not possible for the researcher to attend a team meeting. In these cases it was made very clear through discussion with managers that participation was voluntary and this was reviewed with each participant before arranging the interview time.

It was anticipated that there was a low risk of distress that could be caused by the interview process and its content. However, the participants were provided with the contact details of the researcher to ask any questions prior to, or after the interview.

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Appendices

Appendix 1: Search terms for systematic review

| Database | Search Terms | | | |
|-----------|---|--|--|---|
| PsychINFO | 1. learning\$ disabil\$.mp 2. intel\$ disabil\$.mp 3. mental\$ retard\$.mp. 4. intel\$ impair\$.mp. 5. mental\$ handicap\$.mp. 6. mental\$ deficien\$.mp. 7. mental\$ disabil\$.mp. | 9. exp Intellectual Development Disorder/ 10. devel\$ disabil\$.mp. or exp Developmental Disabilities/ 11. staff.mp. 12. *Caregivers/ 13. Carer\$ | 14. exp Home Care Personnel/ 15. support\$ worker\$.mp. 16. exp Stress/ 17. stress\$.mp. 18. burnout.mp. 19. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 | 20. 11 or 12 or 13 or 14 or 15 21. 16 or 17 or 18 22. 19 and 20 and 21 |
| Embase | 1. mental\$ retard\$.mp. 2. learning disab\$.mp. 3. intel\$ disab\$.mp. 4. mental\$ handicap\$.mp. 5. intel\$ impair*.mp. 6. mental\$ defic\$.mp. 7. mental\$ disab\$.mp. 8. learning disorder/ | 9. exp intellectual impairment/ 10. exp mental deficiency/ 11. development\$ disabil\$.mp. 12. caregiver/ 13. support\$ worker\$.mp. 14. staff\$.mp. 15. *health care personnel/ 16. *stress/ 17. exp burnout/ | 18. burnout\$.mp. 19. stress\$.mp. 20. stress/ or acute stress/ or behavioral stress/ or caregiver burden/ or chronic stress/ or emotional stress/ or job stress/ or mental stress/ or role stress/ 21. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 22. 12 or 13 or 14 or 15 23. 16 or 17 or 18 or 19 or 20 24. 21 and 22 and 23 | |
| Medline | 1. exp Intellectual Disability/ 2. exp Mentally Disabled Persons/ 3. exp Developmental Disabilities/ 4. mental\$ retard\$.mp. 5. intel\$ disab\$.mp. 6. learning disab\$.mp. | 7. intel\$ impair\$.mp. 8. mental\$ handicap\$.mp. 9. mental\$ defic\$.mp. 10. mental\$ disab\$.mp. 11. Stress, Psychological/ or Stress, Physiological/ 12. stress\$.mp. 13. Burnout, Professional/ | 14. burnout\$.mp. 15. staff\$.mp. 16. Health Personnel/ 17. exp Caregivers/ 18. carer\$.mp. 19. support\$ worker\$.mp. 20. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 | 21. 11 or 12 or 13 or 14 22. 15 or 16 or 17 or 18 or 19 23. 15 and 16 and 23. 20 and 21 and |
| CINAHL | S1: TX learning* disabil* OR TX intel* disabil* OR TX mental* retard* OR intel* impair* S2: TX mental* handicap* OR TX mental* deficien* OR TX mental* disabil* OR TX develop* disabil* | S3: (MH "Mentally Disabled Persons") S4: (MH "Developmental Disabilities") S5: (MH "Mental Retardation+") S6: (MH "Health Personnel") S7: (MH "Community Health Workers") | S8: TX Staff* OR TX support* worker* AND carer* S9: (MH "Caregivers") S10: (MH "Health Personnel, Unlicensed") S11: (MH "Burnout, Professional") S12: stress* OR burnout* S13: (MH Stress+) | S14: S1 OR S2 OR S3 OR S4 OR S5 S15: S6 OR S7 OR S8 OR S9 OR S10 S16: S11 OR S12 OR S13 S17: S14 AND S15 AND S16 |
| ASSIA | (staff* OR (support worker* OR carer*) OR (SU.EXACT.EXPLODE("Unlicenced staff") OR SU.EXACT.EXPLODE("Staff")) OR SU.EXACT.EXPLODE("Support workers") OR SU.EXACT.EXPLODE("Home health care") OR SU.EXACT.EXPLODE("Community health workers") OR caregiver*) AND (stress* OR (SU.EXACT.EXPLODE("Burnout") OR SU.EXACT.EXPLODE("Occupational stress")) OR burnout*) AND ((Learning disab*) OR (mental* retard* OR intel* disabi*) OR (mental* disabil* OR mental* defic* OR devel* disabil*) OR (mental* handicap* OR intel* impair*) OR (SU.EXACT.EXPLODE("Learning disabled people" OR "Nonverbal learning disabled people") OR SU.EXACT.EXPLODE("Down's syndrome" OR "Fragile X syndrome" OR "Learning disabilities" OR "Nonverbal learning disabilities" OR "Prader-Willi syndrome" OR "Mental retardation")))) | | | |
| ERIC | (staff* OR (support worker* OR carer*) OR (SU.EXACT.EXPLODE("Home Health Aides")) OR SU.EXACT.EXPLODE("Support workers") OR SU.EXACT.EXPLODE("Home health care") OR SU.EXACT.EXPLODE("Health worker")) AND (stress* OR (SU.EXACT.EXPLODE("Burnout") OR SU.EXACT.EXPLODE("Occupational stress")) OR burnout*) AND ((Learning disab*) OR (mental* retard* OR intel* disabi*) OR (mental* disabil* OR mental* defic* OR devel* disabil*) OR (mental* handicap* OR intel* impair*) OR (SU.EXACT.EXPLODE("Mental retardation" OR "Developmental Disabilities")))) | | | |

NB: MeSH terms denoted by / for PsychINFO, Embase, Medline and SU for ASSIA and ERIC.

Appendix 2: Quality criteria for systematic review

TITLE: Stress Reduction Interventions for Staff Working in Intellectual Disability Services: A Systematic Review

| | Quality Criteria |
|----|---|
| 1 | Aims/ research questions clearly stated. |
| 2 | Demographic and clinical characteristics of groups clearly described. |
| 3 | Sampling strategy. |
| 4 | Use of control group. |
| 5 | Randomisation. |
| 6 | Blinding of allocation to groups. |
| 7 | Sample size based on power calculation. |
| 8 | Outcome measures relevant to intervention and research aims. |
| 9 | Outcome measures were valid and reliable. |
| 10 | Follow-up post intervention. |
| 11 | Intervention appropriately defined. |
| 12 | Intervention fidelity addressed. |
| 13 | Intervention adherence addressed. |
| 14 | Appropriate analysis. |
| 15 | Attrition rates addressed. |
| 16 | Results clearly reported. |

Operationalisation of Quality Criteria

1. Aims/ research questions clearly stated

| | |
|--------------------------------|--|
| 3: Well covered | Aims and hypotheses clearly stated with clear questions and making specific mention of outcomes. |
| 2: Adequately addressed | Aims AND hypotheses stated only briefly or with a lack of clarity. |
| 1: Poorly addressed | Aims OR hypothesis stated |
| 0: Not reported/ not addressed | Aims and hypotheses not reported |

2. Demographic and clinical characteristics of groups clearly described

| | |
|--------------------------------|--|
| 3: Well covered | Demographic and clinical characteristics of groups clearly described e.g. participant's age, gender, setting, job role, extent of experience, service user's characteristics, inclusion and exclusion criteria including means and SD's where appropriate. |
| 2: Adequately addressed | Some (e.g. 4/5 aspects described above) demographic and clinical characteristics described. |
| 1: Poorly addressed | Minimal demographic and clinical characteristics described (< 4 aspects described). |
| 0: Not reported/ not addressed | |

3. Sampling strategy

| | |
|--------------------------------|---|
| 3: Well covered | Participants were randomly selected for the study out of all potential participants and the process was clearly described and of good quality. |
| 2: Adequately addressed | Participants were stated to be randomly selected for the study out of all potential participants but method not described sufficiently to be confident of absence of bias OR selection was not random but some attempt to remove bias from selection process was made OR overall response rate from potential participant pool was 80% or over. |
| 1: Poorly addressed | Sampling was by convenience. |
| 0: Not reported/ not addressed | Sample was selected by authors or employers OR not described. |

4. Use of control group

| | |
|-------------------------|--|
| 3: Well covered | A well-matched control group was used and a suitable intervention control to allow for identification of mechanisms of change. |
| 2: Adequately addressed | A well matched no-intervention control group was used (with results of comparison of groups reported). |

| | |
|--------------------------------|---|
| 1: Poorly addressed | Control group was poorly matched (e.g. differs on significant variables) OR results of comparison of control and experimental groups were not reported OR a multiple time series approach was used (i.e. multiple baseline measurements taken from staggered groups so allow for measurement of changes over same time period for those within intervention and those awaiting intervention). |
| 0: Not reported/ not addressed | No control group. |

5. Randomisation

| | |
|--------------------------------|--|
| 3: Well covered | Random allocation to control and intervention groups was described clearly using an appropriate method. |
| 2: Adequately addressed | Random allocation was described but with details lacking regarding the method used. |
| 1: Poorly addressed | Random allocation was stated but insufficient detail was provided to allow judgement of whether the method was sufficient. |
| 0: Not reported/ not addressed | Allocation to groups was not random OR allocation method not reported. |

6. Blinding of allocation to groups

| | |
|--------------------------------|--|
| 3: Well covered | Blinding of researchers carrying out outcome measurement AND blinding of participants (where appropriate) was clearly described with sufficient detail to judge quality. |
| 2: Adequately addressed | Blinding of participants OR blinding of researchers was described but insufficient detail was provided to allow judgement of whether the method was sufficient. |
| 1: Poorly addressed | Blinding of researchers was stated but not described OR method of blinding was inadequate. |
| 0: Not reported/ not addressed | |

7. Sample size based on power calculation

| | |
|--------------------------------|--|
| 3: Well covered | Sufficient numbers were included based on a power calculation with evidence for effect size estimation. |
| 2: Adequately addressed | Power calculation carried out and sufficient numbers included but with little discussion or justification for effect size. |
| 1: Poorly addressed | Power calculation carried out however insufficient sample size obtained. |
| 0: Not reported/ not addressed | |

8. Outcome measures relevant to intervention and research aims

| | |
|--------------------------------|--|
| 3: Well covered | Outcome measures are clearly linked to research questions/aims, measured all aspects of the concept/s of interest and included a clear rationale for choice of measures. |
| 2: Adequately addressed | Outcome measures are linked to research questions/aims and concepts but not as comprehensive/clearly as could have been achieved. |
| 1: Poorly addressed | Outcome measures are poorly linked to questions/ aims/concepts. |
| 0: Not reported/ not addressed | |

9. Outcome measures were valid and reliable

| | |
|--------------------------------|---|
| 3: Well covered | Psychometric properties of measures are provided with references to publications showing reasonable reliability (e.g. Cronbach's alpha and test-retest correlation coefficient ≥ 0.70) and validity (e.g. construct validity) for relevant population and this data is reported in the paper. |
| 2: Adequately addressed | Psychometric properties of measures are referred to but with few details OR reliability and validity studies are in relation to a different population. |
| 1: Poorly addressed | Measures are described and have face validity but little/no information regarding their psychometric properties is provided OR the measure has poor concurrent/predictive validity and reliability. |
| 0: Not reported/ not addressed | |

10. Follow-up post intervention

| | |
|--------------------------------|---|
| 3: Well covered | Long term (> 6 months) follow-up data are collected. |
| 2: Adequately addressed | Some follow up (3 – ≤6 months) data are collected. |
| 1: Poorly addressed | Post intervention point immediately after the intervention OR (<3mths). |
| 0: Not reported/ not addressed | |

11. Intervention appropriately defined

| | |
|--------------------------------|---|
| 3: Well covered | Intervention is clearly described with reference to: theoretical underpinnings, techniques of intervention, delivery method, the deliverer, timing and duration. Where appropriate, reference to intervention protocol is provided. |
| 2: Adequately addressed | Intervention is described in some detail although parts are less well covered making replication of some aspects difficult. |
| 1: Poorly addressed | Intervention is briefly described with insufficient detail to replicate the intervention. |
| 0: Not reported/ not addressed | |

12. Intervention fidelity is addressed

| | |
|--------------------------------|---|
| 3: Well covered | Details of how the intervention is operationalized (i.e. treatment manual exists/developed) are provided and fidelity to the intervention protocol was assessed and results reported. |
| 2: Adequately addressed | Fidelity to protocol is reported but details are missing OR supervision alone is stated to be provided to ensure appropriate delivery. |
| 1: Poorly addressed | Intervention quality and fidelity is stated but not described OR fidelity checks are carried out and fidelity is poor. |
| 0: Not reported/ not addressed | |

13. Intervention adherence is addressed

| | |
|--------------------------------|---|
| 3: Well covered | Monitoring of participant adherence to intervention (e.g. attendance at multiple sessions or home practice recorded) is described and results reported. |
| 2: Adequately addressed | Monitoring of participant adherence to intervention is partially described and results reported. |
| 1: Poorly addressed | Monitoring of participant adherence is mentioned but not systematically assessed OR adherence is measured and is poor. |
| 0: Not reported/ not addressed | |

14. Analysis is appropriate

| | |
|--------------------------------|---|
| 3: Well covered | Analysis is appropriate to design, matched to measures, deals with confounding variables in a statistically appropriate manner and an explanation for choice of analysis is provided. Sufficient details of analysis are provided to allow replication. |
| 2: Adequately addressed | Analysis is mostly appropriate to design and measures, with sufficient details to allow replication. |
| 1: Poorly addressed | Some aspects of analysis do not provide optimal evaluation of the intervention. |
| 0: Not reported/ not addressed | |

15. Attrition rates and missing data reported and addressed

| | |
|-------------------------|---|
| 3: Well covered | Attrition rates (from allocation to group to final completion of measures) and missing data reported (in all groups where applicable) and dealt with in an appropriate statistical manner (e.g. intention to treat analysis, last known outcome score brought forward) OR were low (below 20%) in control and intervention group. |
| 2: Adequately addressed | Attrition rates were reported and comparisons are made between those who fully participated and those lost to follow-up on relevant variables (e.g. equivalence in baseline stress levels). |

| | |
|--------------------------------|--|
| 1: Poorly addressed | Attrition rates reported but: lacks details OR rates were significantly different between conditions ($\geq 20\%$ difference) Or rates were high ($\geq 20\%$) with no comparisons between groups made or statistical alterations made. |
| 0: Not reported/ not addressed | |
| Notes | Sign 50 states that 20% attrition is considered acceptable. |

16. Results

| | |
|--------------------------------|---|
| 3: Well covered | Results clearly stated with values (e.g. means, SDs) for outcome variables, test statistic, absolute p values, confidence intervals and effect sizes reported as appropriate. |
| 2: Adequately addressed | Results clearly stated with at least 3 of the above details provided. |
| 1: Poorly addressed | Results presented in a narrative fashion with lack of numerical data. |
| 0: Not reported/ not addressed | |

Appendix 3: Participant information sheet

PARTICIPANT INFORMATION SHEET

Staff member's experiences of working with external professionals and behavioural guidelines

Members of staff from your service are being invited to be involved in a research study being conducted as part of a Doctorate in Clinical Psychology. This sheet is to explain the reason for the study and what participation will involve so you can decide if you wish to take part.

Please take some time to read the following information carefully. My contact details are at the end of the sheet if you would like to ask any questions.

What is the purpose of the study?

Behavioural guidelines for people with an intellectual disability and challenging behaviour are often designed with input from professionals outside of the organisations that use them. The aim of this study is to understand how staff experience working with professionals in developing behavioural guidelines. It is hoped that the findings will inform the process of designing future guidelines, leading to improved guidance.

Why am I being invited to participate?

As a staff member of a service which provides support to people with a learning disability you are likely to be expected to follow behavioural guidelines in relation to challenging behaviour that have been developed by external professionals. All participants should have been working for at least four months with at least one individual for whom behavioural guidelines have been written with input from clinical psychologists.

What will participation involve?

You will be asked to participate in an initial interview lasting about an hour. It is intended as an opportunity for you to discuss your experiences of working with external professionals on the development of behavioural guidelines. You will not be asked to disclose the identity of the service users whose guidelines you are discussing.

It is possible that you will be asked to participate in a further interview to follow up on issues that have been raised as the interviews are carried out. All participants will be offered the chance to receive a copy of the findings.

A record of your name will be kept during the course of the data collection and analysis (predicted to end in April 2013) to allow for the researcher to contact participants. This will be kept in a secure location separately from the interview data and will be destroyed once analysis is complete.

All interviews will be digitally recorded, and later transcribed into text form. Recordings of interviews will be deleted once they are transcribed. Facts that you provide during the interview that could allow someone to identify you or the people you work with will be removed from the written text. All the research data will be stored on a password protected memory stick which only the researcher and her supervisors will have access to. It will be kept for at least five years after completion of the study.

As part of the presentation of results, your own words may be used in text form

The information provided will be treated in accordance with Data Protection Act 1998 and NHS Code of Conduct on Protecting Patient Confidentiality. In some situations e.g. if a person discloses an illegal activity or harm to a vulnerable adult, then confidentiality can't be maintained.

Please note:

- ☐ You can decide to stop the interview at any point.
- ☐ You do not have to answer questions if you do not want to.
- ☐ Your name will be removed from the information and anonymised. It should not be possible to identify anyone from the published reports.
- ☐ You can withdraw from the study any time up until the final report is written (October 2013) without giving a reason. If you withdraw, all your data will be removed and destroyed.

What will happen to the findings?

The findings will be written up as thesis for Doctorate in Clinical Psychology and will be submitted to a journal to be published. The findings may also be used in presentations to relevant stakeholders such as NHS or voluntary sector staff members.

How do I participate?

If you do decide to take part it is suggested you keep a copy of this sheet (another copy will be provided at interview). You will be asked to sign a consent form to confirm you understand the details of the study.

If you have any questions or would like to arrange to participate please use my contact details below:

Thank you,

Elly Pegg

Trainee Clinical Psychologist, XXXXXXXX

Email: XXXXXXXXXX

Supervisors:

Karen McKenzie, Senior Lecturer in Clinical Psychology, University of Edinburgh

Telephone: XXXXX

Ethel Quayle, Lecturer in Clinical Psychology, University of Edinburgh

Telephone: XXXXX

Appendix 4: Participant consent form

Consent form

Staff member's experiences of working with external professionals

Please tick the boxes and return to the researcher.

I have read the information sheet and understand that:

| | Yes | No |
|---|-----|----|
| My participation is voluntary | | |
| Information from the research will be kept securely and confidentially for the duration of the study and for at least 5 years after completion. | | |
| I can withdraw from the study at any time until October 2013 and that the audio recording of the interview will be destroyed once it has been transcribed. | | |
| Information I provide will be made anonymous, however there are certain circumstances under which confidentiality can not be maintained. | | |
| The findings will be used in a thesis for a Doctorate in Clinical Psychology, be submitted for publication in academic journals and may be used in presentations and posters. | | |
| I would like to receive a summary of the research findings | | |
| I consent to be contacted again to be offered further participation | | |

Participant Name:

Participant Signature:

Date:

Appendix 5: Ethical review approval letter

Elly Pegg



SCHOOL of HEALTH IN SOCIAL SCIENCE
CLINICAL PSYCHOLOGY

The University of Edinburgh
Medical School
Doorway 6, Teviot Place
Edinburgh EH8 9AG

Telephone 0131 651 3969
Fax 0131 650 3891
Email submitting.ethics@ed.ac.uk

02 April 2013

Dear Elly,

Re: Perceived barriers to the implementation of support guidelines for people with learning disabilities and challenging behaviour: A qualitative analysis

Application for Level 1 Approval

Thank you for submitting the above research project for review by the Section of Clinical Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 21st March 2013.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

Kirsty Gardner
Secretary
Clinical Psychology

NB. Due to the qualitative nature of the project, it was not possible to predict the exact topic area that would be central to the participants at the time of submission to ethics panel hence the title does not match the final project title. This change of focus did not affect recruitment or any other part of the method.

Appendix 6: Interview guide

Interview Guide

Prior to beginning interview:

- Ask participant to read information sheet and offer opportunity to ask questions.
- Ask participant to read the consent form.
- Read through points regarding data storage, use and anonymity.
- Give the participant an opportunity to ask questions and sign form.
- Ask participant to complete background information questionnaire.

Introduce interview covering following points:

- I am interested in your experiences of working with a number of service users.
- This is a chance for you to tell me what you feel is important to the issue, there are no right or wrong answers.
- I won't be asking lots of specific questions but I may want to follow up on something you have said, or check I have understood properly.
- Try not to mention names of service, colleagues or service users but if you do these will be removed from the transcript.

Questions

Initial:

Can you tell me about your experiences of working with clinical psychologists regarding the development of guidelines for challenge behaviour?

Intermediate:

What factors influenced the process of working with clinical psychologists? Have you had any difficult experiences?

Prompts:

Can you explain a bit more about that?

That's interesting, can you tell me more?

Can you give an example of that?

Ending: What do you think is the most important factor you've talked about today?

After reflecting on your experiences we've talked about, is there something you want to add?

Is there anything you want to ask me?

Appendix 7: Background information questionnaire

Background information questionnaire

When analysing the information you provide during the interview it can be very helpful to have some background information.

Age: 16-25, 25-34, 35-44, 45-54, 55-64 Gender: Male / Female

Ethnic group:

1. How long have you been working in a support role with adults with learning disabilities?

.....

2. How long have you been working in your current post?

.....

3. How many adults do you support during an average working day?

.....

4. Thinking about an average working week:

What is your shift pattern (if you have one)?

.....

How long are your shifts?

.....

Do you work alone or with other co-workers?

.....

.....

5. Regarding the behaviour support guidelines you work with

Who writes the guidelines?

.....
.....
.....
.....

Is there input from someone outside your organisation?

.....
.....
.....

Are there general guidelines for working with all service users in addition to person specific guidelines?

.....
.....
.....

Appendix 8: Extract from interviews

| | | |
|--|---|--|
| | Interviewer: Can you tell me about your experiences of working with clinical psychologists on the development of challenging behaviour guidelines? | |
| Being in crisis as context for referral | Participant: Uh-hu, well, thinking about one specific case, we had an emergency referral, um, of a woman who had to leave her family home, in, uh, exceptional circumstances, and, um, she presented with quite challenging behaviour. so we were, (p 2s) we had a little bit, very little input actually from the social work side, but we had, a, um, a consultant clinical psychologist, who took quite a strong interest in the situation. um, and she agreed, she met with us sort of, I think it was about every three months or so, um and basically those meetings consisted of us feeding back our experiences and she would offer, a little bit of, (p 2s) I suppose, how would you describe it, um, (p 3s) I just, I know, it sounds negative, but like, it didn't really, um, like, we never felt she offered anything very concrete in response. | Emergency referral. Exceptional circumstances. Significant CB. Little input from SW. CP taking a strong interest. Regular meetings with CP. Feeding back to CP. Offered something 'little' Lacking in strong guidance from CP. |
| Ppt not wanting to present negative picture? | | |
| | Interviewer: Uh-hu? | |
| | Participant: she would give us things like um she gave us a sheet to fill in, and it was one A4 sheet for a whole month and you were to sort of gauge on a scale of 1 to 5 what her mood had been like each day, it was to pick up on things like, is there a there a pattern involving the service users menstrual cycle, um but, the um, um the sheets that she was giving us were kind of, either, um, too vague, um, or um, I don't know like, um, (p 3s) it was such a crisis moment, there are so many, like, peaks and troughs each day with this service user, that sheet didn't really capture it, so, um, we almost felt that they were almost, they weren't, they weren't completely redundant, but, sometimes you felt you were filling things in, you were putting an arbitrary number on, like, a very complex situation. | Given tasks by CP. Rating mood of SU. Looking for patterns in SU behaviour. Feeling tasks were too vague. Daily peaks and troughs. |
| Not seeing value in tasks set by CP. | | Doing tasks but questioning validity. Complex situation. |
| Lacking info/ support increases desire for input | Interviewer: Uh-hu? Participant: We looked forward to the meetings, because we were really struggling, with something that, (p 2s) especially because there was so little background, this person had no previous support services so there was nothing in her, there was no. | Looking forward to meetings. Struggling. Lacking background info for SU. |

Appendix 9: Author guidelines for systematic review

Journal of Applied Research in Intellectual Disabilities: guidelines for authors

Accessed from: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1468-3148](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3148)

Edited By: Chris Hatton and Glynis Murphy

Impact Factor: 1.098

ISI Journal Citation Reports © Ranking: 2012: 27/51 (Psychology Educational);
33/66 (Rehabilitation (Social Science))

Online ISSN: 1468-3148

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The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peerreviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit <http://authorservices.wiley.com/bauthor/> for further information on the preparation and submission of articles.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have

made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading. The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted.

As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

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